The challenges experienced by the people living with HIV on the termination of temporary disability grant in a semi-urban area in Gauteng.

By

MPOLOKENG CECILIA MOETSELOA

Submitted in part fulfilment of the requirements

for the degree of

MASTER OF ARTS

In the subject

SOCIOLOGY (SOCIAL BEHAVIOUR STUDIES IN HIV AND AIDS)

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: MR L J ROETS

February 2018

Student No: 48798037

DECLARATION

I declare that the study on **The challenges experienced by the people living with HIV on the termination of temporary disability grant in a semi-urban area in Gauteng** is my own work and that all the sources used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

…….. …….. .....

SIGNATURE MOETSELOA MPOLOKENG Date

ABSTRACT

The South African government provides people living with HIV Temporary Disability Grants to assist them with money when they cannot work due to being disabled by HIV. The toll of the disease has contributed to the inability to be employed among black South Africans. The aim of this exploratory qualitative study was to investigate the challenges experienced by people living with HIV when their Temporary Disability Grants are terminated in the semi-urban area of Gauteng. The temporary disability grant is terminated after six months of receiving it. In-depth interviews were conducted with people who live with HIV who are members of Ekupholeni Mental Health and Trauma Centre support group. Thematic analysis was used to analyse data. The findings of the study revealed that the termination of Temporary Disability Grant affects the running of the households of people living with HIV, causes poor management of the disease, non-adherence to treatment which leads to viral rebound, poor nutrition as a result of poor finances. The findings of this study are significant for the policy review on how long a person should receive the disability grant and the criteria used to apply for a disability grant, and to encourage the people living with HIV to start their own gardening programmes for food supply. Moreover, to encourage the introduction of a Chronic Disease Grant (CDG) for people who live with HIV.

KEY TERMS

Disability, disability grants, disability grants recipients, people living with HIV and AIDS, termination of disability grants and antiretroviral treatment.

ACKNOWLEDGEMENTS

I thank my husband Thabo Mokhatla, for his patience and unconditional support while I was pursuing my studies. I thank my children Serati, Reaboka and Nthati for keeping me company at night when I was busy with studies.

I am grateful to my supervisor, Mr L. J. Roets for his encouragement and constructive feedback.

I wish to express my earnest gratitude to my siblings Mapotjo, Khotso and Mantheme for their consistent support, understanding and encouragement.

I would like to express my special thanks to group members of Siyanqoba support group at Ekupholeni Mental and Trauma Centre who participated in this study. I am grateful to Ekupholeni staff for their support and trusting me with their group members. Gratitude also goes to my previous supervisors Mrs Jobodwana and Mr Abraham for their support. Gratitude also goes to my editor Ms Sylvia Audrey Williams.

Above all, I acknowledge the strength from the Almighty, for He has been the pillar of my life.

ACRONYMS

AIDS: Acquired Immune Deficiency Syndrome

ARVS: Antiretroviral

CDG: Chronic Disease Grant

DG: Disability grant

HAART: Highly Active Antiretroviral Therapy

HBM: Health Belief Model

HIV: Human Immunodeficiency Virus

PLWHIV: People living with HIV

PEP: Post-exposure prophylaxis

SASSA: South African Social Security Agency

TDG: Temporary disability grants

UNAIDS: Joint United Nations Programmes on HIV/AIDS

WHO: World Health Organization

Table of Contents

CHAPTER 1: INTRODUCING THE STUDY

1. Introduction

South Africa has extremely high levels of poverty, unemployment and income inequality and the presence of high Human Immunodeficiency Virus (HIV) prevalence worsens the situation. This study is about the challenges experienced by people living with HIV in Gauteng when their temporary disability grants are terminated. South African Social Services Authority (SASSA) working with the Department of Social Development included people living with HIV in the category of candidates who are eligible to receive disability grants in 2003 (SASSA 2017:1). These people are the at a working age but are not working because their bodies are weakened by HIV and AIDS. Due to their disability that hinders them from being employable, they are eligible to apply and receive a temporary disability (SASSA 2017:2). For the criteria followed by PLWHIV when applying for the temporary disability, see chapter 2, 2.6.

Disability grants are awarded to people who are disabled and therefore unable to seek or sustain employment (SASSA 2017:1). For that reason, a disability grant is given either on a 'temporary' or 'permanent' basis. The temporary basis is when the payments are provided for six months up to one year then it is terminated, the individual has to re-apply for further support. While on the permanent basis, the grant usually requires renewal every five years after receiving it (Manuela de Paoli, Mills, & Grønningsæter 2012:2). For more detailed discussion on temporary and permanent disability see chapter 2, 2.5.

Basically, antiretroviral treatment (ARVs) improves the health status of People Living with HIV (PLWHIV) and in addition the Temporary Disability Grant seems to alleviate poverty by empowering them financially. This grant also enables them to contribute to their household by buying of food and sending children to school and being able to pay for children's school fees. As a result of this, the termination of the Temporary Disability Grant affects the lives of people living with HIV negatively as they no longer receive the grants which were provided on the condition that the patient cannot work due to illness (Peltzer 2012:7; Govender, Fried, Birch, Chimbini & Cleary 2015:2)

Therefore, the study was conducted at Ekupholweni Mental and Health Centre where PLWHIV are being provided with psychosocial support.

1.1 Background of the study

In South Africa, HIV and AIDS remains a huge public health problem. The estimated number of people living with HIV was 7.03 million in 2016 (South African Statistics 2016:7). South Africa is one of the countries with the largest roll out of disability grants approximately to 1,070,372 people receiving Temporary Disability Grants which assists in the betterment of PLWHIV's lives (SASSA 2016:1).

South Africa's social welfare system gives grants to people living with disability, children and aged people. Adults from the age of 18 to 65 who are unable to work because of a mental or physical disability are entitled for a means-tested disability grant, consisting of a monthly payment from the state (Kagee 2014:1). The Disability Section of the Social Assistance Amendment Act, (Number 5 Of 2010) states that: a person is eligible for a disability grant, if he or she has reached the prescribed age and is, owing to a physical or mental disability, unfit to obtain by virtue of providing any service, acquiring employment or practising a profession the means required to enable him or her to provide for his or her maintenance (Kagee 2014:1). It also stipulates that the person must not be maintained or cared for in a State Institution and should not receive any social grant (SASSA 2017:3).

The disability grant South Africa Social Assistance (SASSA) uses a Means Test to evaluate the income and assets of the person applying for social assistance in order to determine whether the person's means are below a stipulated amount (SASSA 2017:1). This means test is a way of assessing whether a person deserves to receive a grant as grants are definitely meant for those who have insufficient means to support themselves. The means test differs from one grant type to another (SASSA 2017:7).

SASSA provides disability grants in the form of a temporary and/or permanent grant. For the person to receive a temporary disability grant, the disability will have to continue for a continuous period of not less than six months and not more than twelve months. Whereas for a permanent disability grant, the disability will continue for more than a year (SASSA 2017:3).

In a situation where there is chronic unemployment and deepening poverty, social assistance through a Disability Grant (DG) is made available to adults living with HIV and AIDS who are unable to work because of a mental or physical disability (Govender *et al* 2015:2). The challenges experienced by people living with HIV (PLWHIV) when

their Temporary Disability Grants are terminated relate more to their financial struggle. However, the rate at which the population in South Africa is being infected is declining because PLWHIV are able to access ARVs. (South African Statistics 2016:7). This is because PLWHIV make use the money they receive to pay for transport to fetch the treatment which helps with treatment adherence and compliance (Kagee 2014:2).

Despite the good intentions meant for the Temporary Disability Grant, there are challenges experienced by SASSA and PLWHIV. For PLWHIV, the challenges on the termination are long queues the recipients have to stand on and medical assessments. SASSA experiences challenges when it comes to the huge number of applications it has to process, the shortage of the assessment team and the dependency on the grant (Kelly 2013:4).

1.2 Problem Statement

In this study, the problem is the challenges experienced by PLWHIV when Temporary Disability Grants are terminated. The challenges of terminating these disability grants include non- adherence to the treatment leading to re-infection and viral rebound and also poverty (Kagee, 2:2014). These challenges can results to poor management of HIV and AIDS by patients. This is because people who are living with HIV are no longer adhering to treatment as they no longer have money for transport to fetch their medication (Kagee 2014:2). Moreover, PLWHIV get deep into poverty as they no longer have money to sustain their lives. The fall of the household income disrupts the daily access to food and they end up seeking money through loans, which are not easy to pay back (Guruta & Tanga 2014:106). These challenges will be discussed in details in chapter 2.

1.3 Purpose of the study

The purpose of this study is to understand the challenges experienced by the people living with HIV in Gauteng on the termination of the Temporary Disability Grant and also to know how these challenges are affecting their wellbeing. Furthermore, it is to share the research findings with relevant stakeholders including the Centre on how to improve the support the PLWHIV need during the termination of their Temporary Disability Grant.

1.4 Objectives of the study

The objectives of this study are as follows:

1. To explore the challenges experienced by PLWHIV when their temporary disability grants are terminated.

2. To explore the effects of the termination of temporary disability grants on the lives of PLWHIV.

3. To explore the importance and the contribution the Disability Grants (DG) do in the lives of PLWHIV.

4. To investigate whether increasing the time frame for receiving the Temporary Disability Grant can help to address the problems caused by the termination of disability grant.

1.5 Research Questions

Research questions are used to navigate around the problem statement (Babbie 2013:70). The research questions also help to shape the research study and to give it a direction (Punch 2011:36). The research questions are used to explore the challenges experienced by PLWHIV on termination of temporary disability grant. Specific questions pertinent to this study are:

1. What are the challenges experienced by PLWHIV when Temporary Disability Grants are terminated?

2. What are the effects of termination of Temporary Disability Grants on the family of temporary disability recipients?

3. How can Temporary Disability Grant be administered to address these challenges?

4. What is the importance of the contribution made by the Temporary Disability Grants (TDG) in the lives of PLWHIV?

1.6. Significance of the study

The significance of the study is to gain insight and to understand the challenges experience by PLWHIV on the termination of the Temporary Disability Grant. Moreover, to encourage the Ekupholeni Mental Health and Trauma Centre to continue raising awareness on HIV and AIDS. Also, to contribute more to the research done on

the challenges experienced by PLWHIV on the termination of the Temporary Disability Grant.

1.7. Definition of Key Terms and Variables

- People living with HIV (PLWHIV): People who tested HIV positive.
- Disability grant recipients: Are people who by the virtue of the South African Social Assistance Bill of 1992 section (1), are defined as “any person who has attained the prescribed age and is, owing to his/her physical or mental disability, or is unfit to obtain any service employment or profession, can apply for the finance needed to enable him/her to provide for her maintenance” (SASSA 2017:7).
- Disability grant: The DG programme in South Africa includes the qualification for people living with HIV and AIDS to have a low CD4 count, which is a biological marker for illness due to HIV/AIDS. (Haber, Fink, Bärnighausen, Bor, Cohen, Tanser & Pillay 2017:2). SASSA provides disability grants in a form of temporary and permanent grants. For a person to receive a permanent disability grant, the disability will continue for more than a year. Whereas for the temporary disability grant, the disability must continue for a continuous period of not less than six months and not more than twelve months. The study will focus on the latter one.
- Termination of disability grants: The process of discontinuing the issuing of the disability grant to its recipients (Manuela de Paoli *et al* 2012:1).
- Effects of termination of disability grants: any negative experiences people living with HIV may have when their temporary grants are terminated.
- Semi-urban: Is a place between the urban and rural areas. It is somewhat, but not wholly characteristic of urban areas (Collins English Dictionary 2006). A semi-urban area is between urban and rural, or partly areas that either are situated geographically in between city and countryside (Meeus & Gulinck 2008:10).

1.8. Research process

A qualitative, explorative design was used in this study. The researcher conducted in-depth interviews with the participants at the centre. The participants were PLWHIV

from Ekupholeni Mental Health Centre, in Katlehong, Gauteng. The data was collected from 9 participants aged from 35 to 58. Data collected from in-depth interviews was analysed using thematic content analysis. The interpretation of the data from the coding process and themes derived after content analysis were summarised into findings. The research methodology is discussed in more detail in Chapter 3, while the findings of the study are discussed in Chapter 4.

1.9. Conclusion

In conclusion, the purpose of this study is to explore the challenges experienced by PLWHIV in Gauteng on the termination of the temporary disability grants and how that affects their lives. The research questions were used to explore the results of terminating the temporary disability grant and seek to understand the challenges that are experiences by the PLWHIV when their disability grants are terminated. Moreover, to help with the understanding and importance of these disability grants in the lives of people who live with HIV and AIDS. In the next chapter, a literature review is used to gain a theoretical understanding on what previous researchers said about the topic as well as to apply some relevant social behaviour theories.

1.10. Chapter Outline

This dissertation is divided into five chapters that are arranged as follows:

Chapter 1

This chapter is on the introduction and background to the study. It also includes the problem statement, the purpose of the study, the significance of the study, terminologies used in the study and research questions. Research process and the chapters outline are also part of this chapter.

Chapter 2

This chapter discusses the relevant literature pertaining to the study and the theoretical framework used for the study on. The literature review of the current academic debates on disability grants, termination of disability grants, challenges and the effects of the termination of disability grant and different types of grants offered by SASSA will be discussed.

Chapter 3

The chapter describes the research methodology and design used by the researcher on the study. The study population and sampling methods are also provided. Furthermore, the chapter provides data collection methods and the ethical consideration of the study. Finally, the chapter also presents the data analysis tool used by this study.

Chapter 4

This chapter explains and discusses the research findings of the study. Thematic analysis is used to analyse the data. Codes and themes that emerged from the in-depth interviews are presented and discussed.

Chapter 5

This chapter forms the conclusion of the study. The key findings and study's limitations are presented in this chapter. The chapter concludes with the recommendations of the study.

Chapter 2: LITERATURE REVIEW

2.1. Introduction

This chapter describes what previous, current literature and research has to say about the challenges experienced by the people living with HIV (PLWHIV) on the termination of a temporary disability grant. The literature review helps to establish the link between what the researcher proposes to examine and what has already been studied (Kumar 2014:48). Therefore, this chapter will cover literature on HIV and AIDS prevalence in South Africa, disability and HIV and AIDS, disability grants, Models used to describe disability, Disability grants in South Africa, challenges experienced by PLWHIV on the termination of temporary disability grant and finally the theoretical framework will be discussed.

2.2. HIV and AIDS prevalence in South Africa

According to WHO (2015:1), globally more than 70 million people have been infected with the HIV and AIDS. In addition, Sub-Saharan Africa remains most affected, with nearly one in every 25 adults (4.2%) living with HIV (WHO 2015: I). South Africa has the biggest and highest profiled HIV epidemic in the world, with an estimated seven million people living with HIV in 2015 (UNAIDS 2016:1). As the result, the South African government introduced the disability grant that can be either temporary or permanent.

2.3. Disability and HIV and AIDS

South African Department of Labour (SA DoL 2017:8) defines disability as a long term or recurring physical or mental impairment which noticeably limits the prospects of entrance into or advancement in employment. The World Health Organization (WHO) defines disability as multidimensional which includes body function or structure, activity limitation and participation restriction experienced by individual in the involvement in life. It encompasses different models to define disability (WHO 2011:3). According to the South African Department of Labour (SA DoL 2017:2), the prevalence of disability in South Africa ranges from between 10% to 26% of the SA population, including PLWHIV.

2.4. Models used to describe disability

Models are used to provide a basis upon which government and society can develop strategies for meeting the needs of disabled people (Smart 2014:1). Models of

disability are essentially devised by people about other people and they provide an understanding into the attitudes, conceptions and prejudices towards people with disability including people who are infected with HIV (Masoudnia 2015:3). Finally, models reveal the ways in which society provides or restricts access to work, goods, services, economic influence and political power for people with disabilities without taking into consideration their ability (Smart 2014:3). Different models for disability are discussed next.

2.4.1. Social Model of disability

The Social Model views disability as a consequence of environmental, social and attitudinal barriers that prohibit people with impairments from full participation in society. The Social Model of disability states that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at means of removing barriers like prejudice and discrimination of PLWHIV that limit life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives (Smart 2014:29). Meanwhile, the Social Model of Assistance argues that physical and mental disability is not the only factor or primary issue that stops poor people from finding work and making an income to support themselves and their families, but unemployment does (Leibbrandt, Lilenstaein, Shender & Wooland 2013:2).

2.4.2. Medical Model of disability

The Social Model of disability states that disability is caused by the way society is organised, whereas the Medical Model of disability says people are disabled by their impairments like forgetfulness and blindness that is caused by ARVs treatment of PLWHIV. Under the Medical Model, these impairments, or differences should be 'fixed' or changed by medicine and other treatments, even when the impairment or difference does not result to pain or illness. Disability is related to the functional limitations of the individual or physical handicap (Kelly 2013:14).

The Medical Model looks at the physical alignments of PLWHIV and not what the person needs. It makes low expectations of life and leads to people losing independence, choice and control in their own lives as it declares disability (Smart 2014:14).

2.4.3. Expert/Professional Model of Disability

The Expert/Professional Model has provided a traditional response to disability issues and can be perceived as an offshoot of the Medical Model. Within its framework, professionals follow a procedure of classifying the impairment and its limitations by using the Medical Model. The professionals take the necessary action to recover the position of the disabled person for better functioning of the person (Smart 2014:31). As it happens with the medical personnel, they identify the PLWHIV who deserve to be awarded temporary disability grants based on the physical wellness of the person and thus based on the CD4 count.

2.4.4. Economic Model of Disability

Economic Model of disability is defined by a person's inability to participate in work. It also measures the degree to which impairment affects an individual's efficiency and the economic consequences for the individual, employer and the state. Such concerns include loss of earnings of the individual and payment for assistance to the individual; lower profit margins for the employer connected to the impairment of the disabled employee; and state welfare payments such as the temporary disability grant (Smart 2014:21; SASSA 2016:3). With termination of the temporary disability grant, the economic impact affects the recipients in a way that it becomes impossible for them to adhere to treatment as they struggle with the cost of transport to fetch that treatment (Govender *et al* 2015:9).

The Economic Model is used primarily by policy makers to assess the sharing of benefits for those who are unable to take part fully in work. However, Social security benefits provided by SASSA are not designed to remove disabled people from poverty as PLWHIV experienced the termination of their Temporary Disability Grant. The policy makers need to balance equity, which is the right of the individual to self-fulfilment, and the social contribution through work and efficiency (Smart 2014:21).

The Economic Model that is used in South Africa to issue the temporary disability grant ensures that only people living with HIV and who are at the point of death, receive assistance in the form of money (Gutura & Tanga 2014).

Nonetheless, the Medical Model of Disability and the Expert/Professional Model are used to instruct the medical personnel who are responsible for endorsing patients for disability grants to review whether they are able to work, irrespective of the availability

of work (Govender *et al* 2015:2). As such, the South African Social Service Agency (SASSA) uses the Economic Model of Disability to issue a Temporary Disability Grant (TDG) based on the fact that they cannot work due to disability associated with HIV and AIDS (Manuela de Paoli *et al* 2012:2).

For this study, the Expert/Professional Model of Disability describes the disability of PLWHIV through medical assessment by the qualified Medical Doctor to ascertain the degree and severity of disability. The Medical Doctors also recommend and approve applications for temporary disability grants based on the findings of the assessment.

2.5. Disability grants in South Africa

The South African disability grant is a non-contributory, means-tested cash transfer available on a permanent or temporary basis to people found unfit to work as a result of functional impairment and who do not have adequate means of support (Kelly 2013:2; SASSA 2017:3). Social security is granted in the form of money the state issues for people living with disability. The grant is in a temporary and/or permanent form. The grant is given to all severely physically and mentally disable people that are older than 18 and younger than 65 years (SASSA 2017:3). The recipient should be a resident in South Africa, must submit a medical or assessment report confirming disability including those who are disabled by HIV and AIDS. The report should not be older than three months, the recipient must not be cared for in the state institutions and should not be receiving any social support grant (SASSA 2017:3). The disability grant amounts to R1510.00 per month (South African Social Service Agency (2017:6).

The issuing of social support grant is done according to the South African Bill of Rights (Number 108 of 1996, Section 27 (1) (c) which stipulates the right to social assistance as it states that “everyone has the right to have access to social security and appropriate social assistance, including, if they are unable to support themselves and their dependents”.

The disability grant is an important element of South Africa’s social security system, and plays a crucial role in decreasing poverty among PLWHIV. Moreover, it offers financial assistance to individuals who are considered disabled and consequently they are unable to seek or sustain employment (Manuela de Poli *et al* 2012:2). It is intended for people who are sick and not working to sustain their living, including PLWHIV. The disability grant (DG) programme in South Africa includes the qualification for PLWHIV

of having a low CD4 count and being physically sick due to AIDS related diseases (Haber, Fink, Bärnighausen, Bor, Cohen, Tanser & Pillay 2017:2).

Moreover, the disability grant (DG) is seen as macro-finance because the money is often used more generally in the household, and also used for purposes like taking care of other family members' needs other than the income maintenance of the person who is living with HIV and who is the recipient of the grant (Knight, Hosegood & Timaeus 2013:1). However, according to the study conducted by Knight *et al* (2013:2) on the 'South African disability grant, the influence on HIV treatment outcomes and household well-being in Kwazulu-Natal', there is enormous pressure on the individual grant beneficiary to maintain their grant. This is due to the access to Antiretroviral (ARVs). The availability of ARVs encourages adherence to the ARV medication resulting to a healthier person. The implication of this is that many people living with HIV stand to lose the grant as a result of their improved health and are no longer regarded as people with disability because they qualify for labour market (Knight *et al* 2013:2; Govender et al 2015:5).

2.6. Recipients of disability grants

Recipients of disability grants are people whom the South African Social Assistance Bill of 1992 (number 59) Section (1), defines as persons who have suffered disability that has affected their mental and physical ability and that hinders them from being employed. They can apply for the finance required to enable them to afford their maintenance (SASSA 2016:13).

The criteria the recipients have to meet in order to qualify for the temporary disability grant state that according to the South African Social Service Agency (2016:3), men should be in the age range of 18 to 65, women must be younger than 60. An applicant should not receive any other grant from the government and should not be under any state's care. Applicants should not be working due to their disability; the disability should be continuous for more than six months, but not continuous for more than a year. For PLWHIV, a state appointed doctor should assess and confirm the disability. The physical assessment includes checking if the CD4 count is 500 cells/mm or below, this is a biological marker for illness due to HIV and AIDS (Govender *et al* 2015:2; Haber et al 2017:4; Manuel de Poli *et al* 2012:2).

In Uganda, on the contrary, the government provides micro-finance to people with disability. The criterion the Uganda government uses is that the people with disability should have been economically inactive in the last twelve months because of disability and the criterion does not exclude or specify HIV and AIDS. In contrary, in South Africa the CD4 count and physical health of a person is considered important when awarding the temporary disability grant (Nuwagaba, Nakabugo, Tumukunde, Ngirabakunzi, Hartley & Wade 2012:2).

2.7. Termination of temporary disability grant

The disability grant termination happens when patients who are on Highly Active Antiretroviral Therapy (HAART) experience viral load suppression and are looking healthy enough to work. This happens after six months of receiving the temporary disability grant (Govender *et al* 2015:2; Manuela de Poli *et al* 2015:2). According to SASSA (2016:3), the disability grant is intended to help people who are unemployable due to weak bodies to sustain living (SASSA 2016:3). In addition, cash transfers do have the possibility of breaking the lasting inter-generational transfer of poverty if used for security in human capital such as education. Inter-generational transfer of poverty means children who are born from the family experiencing poverty might end up being poor because their parents may lack finances to take care of their education. Human capital investment is attained through using grant money to enrol children at school and encouraging good health through regular medical check-ups and good nutrition (Leibbrandt, Lilenstaein, Shender & Wooland 2013:2).

Termination of the temporary disability grant at six or twelve months affects the lives of PLWHIV in a negative manner. The reason being that the PLWHIV are left with no money to sustain life. Therefore, the management of HIV and AIDS will be negatively affected. Finally, unemployment and the loss of the grant may escalate food insecurity, which could have severe consequences for individuals on ARVs, given the need for good nutrition to ensure treatment efficacy (Manuel de Poli *et al* 2012:2)

2.8. The Challenges of terminating the temporary disability grant

The relationship between HIV and AIDS and poverty is evident in the fact that disability is closely connected to poverty. This is because both a cause and a consequence of poverty increase the risk of disability in PLWHIV when they are unemployed or lacking money to sustain life (Setswe 2015:4). For example, this can take place through the

inability to access healthcare and the resulting poor nutrition when the termination of the temporary disability grant happens (Govender *et al* 2015:5). This is due to the fact that PLWHIV depend on the temporary DG money for transport to fetch their treatment and to buy nutritious food that will help with building strong immunity which in turn helps with fighting the virus. Therefore, by terminating the TDG, the government overlooks the fact that the treatment alone is not effective if it is not combined with proper nutrition and economic empowerment. For that reason, the termination of the temporary disability grant brings challenges to its recipients (Guruta & Tanga 2014:665).

Furthermore, termination of temporary disability grant exposes PLWHIV to the risk of poverty, for example due to the costs related to the disability, when one has to pay extra money for treatment, one experiences discrimination in the labour market or marginalisation from education resulting from absenteeism due to being sick. People with disability are excluded from activities that can help them to avoid poverty such as being employed, the reason being their bodies are weakened by HIV and AIDS. This means that PLWHIV are more likely to experience discrimination that results in financial complications and socio-economic deficiency owing to the termination of the temporary disability grant (Govender *et al* 2015:5; Setswe 2015:4). Moreover, PLWHIV get deep into poverty as they no longer have money to sustain their lives. The fall of the household income disrupts the daily access to food and they end up seeking money through loans, which are not easy to pay back (Guruta & Tanga 2014:106).

PLWHIV can be caught in a vicious cycle of poverty and disability, each being both a cause and a consequence of the other. They qualify for theTemporary Disability Grant when they are not employed which can be related disability. They also qualify to apply for the grant when they have no means of supporting themselves financially. Consequently, terminating the Temporary Disability Grant will result in poverty and disability as they will not have money to treat the disease (Govender *et al* 2015:8).

2.9. The socio-economic impact of terminating temporary disability grants on PLWHIV

The termination of the Temporary Disability Grant may propel the families of the people depending on it into more poverty. As Knight *et al* (2013) states in their research, the socio-economic impact of HIV and AIDS such as the inability to work due to discrimination and prejudice serves to make a cruel cycle of poverty and disease. This means that due to the poverty South Africa is facing, when PLWHIV experience the termination of Temporary Disability Grant, their socio-economic status collapse and they can experience poverty because they are unable to afford food and other life necessities, and are also unemployed.

Socio-economic impact of termination of Temporary Disability Grant is also seen when PLWHIV are facing challenges of life requirements such as paying for children's school fees and buying clothes (Guruta & Tanga 2014:175). The fact is that when an adult member of the family gets sick, he or she will have to leave work and that will result in a fall in the household income (Steinert, Cluver, Melendez-Torres & Romero 2016:3).

Apart from that, the termination of a Temporary Disability Grant leads to elevated demand for access to disability grants as this is a better way of making money due to the scarcity of jobs (Guruta & Tanga 2014).

Moreover, PLWHIV residing in a semi-urban area, which is a place between the urban and rural areas (Collins English Dictionary 2006; Meeus & Gulinck 2008:10); experience major socio-economic conditions than PLWHIV residing in rural area (Pienaar, van Rooyen & Walsh 2017:1). The results of the study conducted by Pienaar, van Rooyen and Walsh (2017) on 'Household food security and HIV status in rural and urban communities in the Free State province, South Africa', showed that a high percentage of respondents in all areas experienced running out of money to buy food, and this happens more among urban HIV-infected persons than HIV-uninfected persons. The study also revealed that more HIV-infected urban respondents compared to their uninfected counterparts depend on inadequate food to feed their children. The study also states that although a large percentage of rural respondents reported periods of food shortage, in the urban area it was much higher. In urban areas, more HIV-infected respondents reported periods of food shortage compared to HIV-uninfected respondents (Pienaar, van Rooyen & Walsh 2017:5).

The termination of the disability grant also affects PLWHIV in the semi-urban areas because they cannot borrow money from anyone as they have left their family members behind in the rural areas (Pienaar, van Rooyen & Walsh 2017:12).

For PLWHIV living in the semi-urban areas, accessing healthcare also complicates life as they need money for transport. Apart from transport, living in the semi-urban areas, requires one to have money to buy food, unlike in the rural areas where the soil is tilled and food is produced (Pienaar, van Rooyen & Walsh 2017:12).

Living in a semi-urban area, one needs to work at a particular job in order to earn money. However, chronic illness, together with the need to care for the ill members of the household, results in valuable time being taken away from the job. This leads to loss of income and exposes the household to the risk of food insecurity (Pienaar, van Rooyen & Walsh 2017:4).

Unemployment also mostly affects PLWHIV who live in the semi-urban areas. This is because there is a high competition for jobs as the number of people living there is higher than in the rural areas. The unemployment also affects access to food which is regarded as a necessity (Pienaar, van Rooyen & Walsh 2017:1).

2.10. Management of HIV and AIDS by PLWHIV

The importance of good nutrition in the proper absorption of medication is an essential component of adherence (Shubber, Mills, Nachega, Vreeman, Freitas & Bock 2016:5). Poor nutrition is often linked to adverse outcomes in HIV and AIDS treatment. This is because poor nutrition may expose PLWHIV to the progression of HIV to AIDS. Besides, the absence of good nutrition in patients on ART leads to poor ART adherence outcomes, which may lead to viral rebound. The viral rebound is when the person on the antiretroviral therapy (ART) has persistence, detectable levels of HIV in the blood after a period of undetectable levels. The cause may include drug resistance or poor adherence to HIV treatment regime (Omole & Semenya 2016:5)

Poor adherence was found to be due to the pain caused by taking treatment without eating food, hence poor adherence may lead to poor management of HIV and AIDS (Azia, Mukumbang & Van Wyk 2016:2). Adding on that, food insecurity has been documented as a common and an important barrier to taking medication according to prescription, which also contributes to poor management of the disease by PLWHIV.

Last, lack of money for transport is another contributing factor as PLWHIV do not have money for transport to seek medical care and to access ARV (Govender *et al* 2015:3; (Omole & Semenya 2016:5)

2.11. Profile of Ekupholeni Mental Health and Trauma Centre

Ekupholeni Mental Health and Trauma Centre is a registered non-governmental organisation (NPO 035-007) that provides psychosocial counselling to victims of trauma. It operates within the Kathorus area, a semi-formal settlement 25 kilometers outside Johannesburg. The settlement houses a community of 2.5 million people. The region consists of former Black locations and sprawling informal settlements, including Katlehong, Vosloorus, Tokoza, Zonkezizwe, Palm Ridge, Phola Park, and Tsietsie, amongst others. The centre includes public clinics and a hospital. It operates in zozo huts (prefabricated buildings) and containers at nine different locations. Ekupholeni Mental Health and Trauma Centre is a place of healing which strives to reach individuals, families, groups and communities in distress and to engage them in a holistic process of healing, recovery and empowerment.

Ekupholeni was founded in 1994 to address the needs of a community traumatized by the political violence of the 1980s/90s, as well as by poverty, unemployment, criminal and gender violence, substance abuse, family breakdowns, school absenteeism and gang activity.

The centre continues to provide relevant support for the region's changing needs. One of the biggest problems in Katorus is the overwhelming prevalence of HIV and AIDS. Of increasing concern is the numerous children and youth who have been orphaned by the pandemic and are also infected by it. So far, Ekupholeni is the only organization providing holistic psychosocial support services in this community in relation to HIV and AIDS. The centre provides support groups for PLWHIV, it also provides food for PWLHIV, it informs them about the temporary disability grant and the procedure they should follow when applying for the grant.

Services provided by the centre are:

2.11.1. HIV and AIDS and Bereavement Programme

This programme focuses on children, youth and adults who are infected and affected by HIV and AIDS. Ekupholeni provides the following services: individual and group

counselling to infected children, youth and adults; individual and group bereavement counselling for affected children, youth and adults; psychosocial and material support for child-headed households; psychosocial support for health workers in the HIV field intensive programmes for bereaved primary school children and community healing services.

The programme also aims to prevent the spread of HIV by raising awareness about the virus and educating the community about how it is spread, how to avoid exposure, how to avoid infecting new-borns, how to take ARVs, and when to use post-exposure prophylaxis (PEP).

2.11.2. Gender-based Violence Programme

The Gender team provides much needed psychosocial support to survivors of rape, sexual assault and domestic violence from their base at the Thelle Mogoerane Thuthuzela Care Centre.

Every month the centre sees about 100 new rape victims, about 60% of whom are children. As part of the multi-stakeholder responsibilities of the Thuthuzela Care Centre, it acts as advocates for rape victims, assisting clients to lay charges against perpetrators, familiarizing them with legal terms, and accompanying them to court.

The centre also does intensive counselling with children who are sexually abusing other children, often as a result of having been abused themselves. It encourages legal action against abusers and, as part of its commitment, runs court preparation workshops with caregivers of sexually abused children and youth. It does individual court preparation with the children and youth.

The programme also aims to prevent gender violence by raising awareness about domestic violence (Domestic Violence Campaign), inappropriate sexual behaviour (Don’t You Touch Campaign), and child protection (Children’s Rights Campaign).

The services provided by Ekupholeni Mental Health and Trauma Centre encourage PLWHIV to adhere to treatment as they are given food parcels to survive on, even when their temporary disability grants are terminated. It educates PLWHIV about the importance of adhering to the treatment and the results of not taking treatment as told to do by the doctor. The centre also helps PLWHIV to alleviate poverty by encouraging them to start their own gardens.

2.12. Theoretical framework

Theoretical framework is a systematic justification of the observations that relates to a particular aspect of life (Babbie, 2013:8; Tzanakis, 2013:1). The Social Capital Theory and Health Belief Model will be used to shape this study.

2.12.1. Social Capital Theory

The Social Capital Theory is defined as networks, shared norms, values and understandings that facilitate co-operation within and among groups (Rocco & Suhrcke 2012:1). This theory will be used to explain the importance of the temporary disability grant in PLWHIV's lives. Social Capital can be defined as the intangible assets that are important in the daily lives of people, like goodwill, fellowship, sympathy, and social intercourse among the individuals and families who make up a social unity (Rocco & Suhrcke 2012:2). Coleman (1988) refers to social capital as the social structure that can contribute to actions of individuals within the social structure itself. Moreover, social capital can be seen as the established obligations, expectations and trustworthiness of the families of PLWHIV towards the temporary disability grant. Putnam's definition points to the role of social capital as a substance of cooperation, a vital device to attain better economic outcomes where the PLWHIV are receiving the temporary disability which helps with alleviating poverty (Rocco & Suhrcke 2012:1).

This theory is used because it is efficient at the meso level which refers to the group of people. It explains TDG as the money that can be utilized to make the micro-macro transition, meaning the money PLWHIV receive does not only support the recipient, but also other family members. It pays for children's school fees, contributes to the running of the household and the taking care of other family members (Tzanakis 2013:5).

The Theory of Social Capital also confirms the association between poor environmental quality and the general status of health. This theory fits in this study because the lives of PLWHIV become better as they receive income that leads to a better life. PLWHIV are then able to support themselves and their families through the money they receive as the Temporary Disability Grant (Rocco & Suhrcke 2012:1).

In addition, the Temporary Disability Grant helps the recipients to meet the basic household and health needs. The social capital is often the only type of support

available to protect those living with disability or chronic illness from the major shocks of the vulnerable context that almost always affects their socio-economic status (Guruta & Tanga 2014:4). Social capital is also seen as a network group where PLWHIV can share their experiences on how to deal with challenges they experienced when their Temporary Disability Grant was terminated (Campbella, Scotta, Nhamoa, Nyamukapab, Madanhire Skovdalc, Sherrd & Gregson 2013:3). Moreover, social capital as a social network group is found to be helpful with adherence to treatment. Social capital may decrease both the perception and experience of stigma experienced by PLWHIV caused by the termination of the Temporary Disability Grant, thus influencing HIV treatment adherence (Mukoswa, Charalambous & Nelson 2017:1).

The different types of social capital include the following:

2.12.1.1. Bonds social capital

Bonds are explained as links to people based on a sense of common identity with "people like us", such as family, close friends and people who share the culture or ethnicity. This is also seen with the disability grant recipients when they form groups to help them overcome the trials resulting from the termination of the Temporary Disability Grant (Hawkins & Maurer 2010:4).

2.12.1.2. Bridges social capital

Bridges are links that go beyond a shared sense of identity, for example they include distant friends, colleagues and associates. Bridging and linking social capital are exchanges in which people provide and share information, resources, supplies and food that can be helpful to PLWHIV during the termination of a disability grant (Hawkins & Maurer 2010:4; Hunt, Durham & Menke 2015:2).

2.12.1.3. Linkages social capital

Linking social capital is the result of the weakest relationship, but having the most valuable outcome, as linking offers access and connection to power organisations and institutions. The PLWHIV can be linked to Non-Governmental Organisations (NGOs) that can be helpful to the group of PLWHIV (Hawkins & Maurer 2010:4).

2.12.2. The Health Belief Model

The Health Belief Model (HBM) was developed in the early 1950s by Irwin M. Rosenstock, Godfrey M. Hochbaum, S. Stephen Kegeles, and Howard Leventhal

(Rosenstock 2016:1). The model specifies that if individuals detect a negative health result to be severe, they perceive themselves to be prone to it, and recognise the benefits to behaviour that decreases the likelihood of that outcome to be high, and perceive the barriers to adopting those behaviour to be low, then the behaviour is likely to be opted by those individuals (Carpenter 2010:1).

The model was used to describe how PLWHIV responded to the termination of Temporary Disability Grant by adhering to treatment regardless of the challenges brought by the termination of their grant. The theory describes the process of change in relation to health behaviour (Tarkang & Zotor 2015:1). The HBM originates from psychological and behavioural theory with the base that the two components of health-related behaviour are required for someone to avoid illness and yet to be in an AIDS stage. Adhering to the treatment even when the temporary disability grant is terminated showed that PLWHIV understand the consequences of stopping taking the treatment, or of getting healthy if already ill and the belief that a specific health action will prevent or cure illness (Tarkang & Zotor 2015:2).

The HBM suggests that one's belief in the personal threat of an illness coupled with a person's faith in the effectiveness of the suggested health behaviour will predict the possibility that the person will assume the behaviour of continuing with the treatment regardless of the scarcity of food which is a challenge posed by the termination of the temporary disability grant. The model continues to highlight that an individual's course of action commonly depends on the individual's understanding of the benefits and barriers linked to health behaviour and how strongly they believe that they are vulnerable to the disease in question (Tarkang & Zotor 2015:1).

Six constructs of the HBM.

2.12.2.1. Perceived susceptibility

This refers to a person's own understanding of the danger of contracting disease. PLWHIV feel that they may get to the AIDS stage where opportunistic diseases are complicating their lives if they do not take treatment accordingly (Tola, Shojaeizadeh, Tol, Garmaroudi, Yekaninejad, Kebede, Ejeta, Klinkenberg, Klinkenberg & Kassa 2016:3). An individual's belief that he/she is susceptible to HIV and AIDS progression can encourage him/her to take medication regardless of the grant availability.

2.12.2.2. Perceived severity

This construct claims that one's feelings about the seriousness of contracting the disease, or leaving the disease untreated may lead to severe results. One's belief of how serious a condition is and its consequences are will encourage certain behaviour (Moattar, Roozitalab, Gholamzadeh, Firoozi & Zare 2014:3). An individual's belief that the HIV to AIDS progression has severe consequences if the medication is not taken accordingly affects their behaviour. The disruption of taking medication is due to the termination of the Temporary Disability Grant which affects their finances needed to fetch the treatment. PLWHIV are aware of the importance of not stopping to take medication as this might results to unwanted consequences like AIDS related disease or death (Manuela de Poli *et al* 2014:4).

2.12.2.3. Perceived benefits

This refers to one's understanding of the success of various actions accessible to reduce the threat of disease. Adhering to the treatment regardless of the results brought about by the termination of the grant is an action the PLWHIV are taking (Manuela de Poli et al 2012:2). For the person to decide on taking the action of preventing and controlling the disease depends on the consideration and assessment of both perceived susceptibility and perceived benefit. The PLWHIV believe that receiving the Temporary Disability Grant will help them to adhere to their ART and it will reduce the proneness to AIDS progression or the severity of the disease shows perceived benefits of having grant.

2.12.2.4. Perceived barriers

The barriers include the person's feelings about the obstacles, such as the termination of the Temporary Disability Grant that can contribute to hindering the individual from performing a recommended health action of adhering to the ARV treatment. In the case of PLWHIV, the termination of the Temporary Disability Grant is one of the barriers to conforming to treatment. This is because the grant assists them to buy food and pay for transportation to collect medication. The person evaluates the efficiency of the actions against the perceptions that it may be expensive, dangerous and unpleasant to stop treatment. The PLWHIV belief that the materials, physical and psychological costs of adhering to ART outweigh the barriers, which in this case is the termination of the temporary disability grant (Tarkang & Zotor 2015:5).

2.12.2.5. Cue to action

Cues to action are when an individual feels the desire to take the appropriate action after considering that one is able to do so (Afe, Motunrayo & Ogungbade 2017:3). The individual's exposure to factors that prompt adherence to ART promote that desire (Tarkang & Zotor 2015:5). PLWHIV consider the termination of the Temporary Disability Grant as the barrier that can be dealt with by borrowing money for taxi fares to collect their medication in order to avoid resistance to ARVs treatment

2.12.2.6. Self-efficacy

This is the strength of an individual's belief in one's own capability to act on tough situations and to deal with any linked to obstacles. Self-efficacy is one's ability to effectively take action (Tarkang & Zotor 2015:5). The PLWHIV's confidence that they can adhere to ART depends on the accessibility of the temporary disability grant that can enable them to buy food they need before taking the treatment (Adefolalua, Nkosia, Olorunjub & Masemola 2014:4).

Social capital theory and HBM are the corner-stone of survival for the PLWHIV. Having networks of people that can advise and support one to continue with the treatment can help to overcome the challenges that are related to the termination of the Temporary Disability Grant. HBM also acts on the individual level in assisting PLWHIV to adhere to treatment and avoid things that can hinder them from better management of the disease. These theories are at the individual and meso/community levels and as the study is also a new study it is an explorative study.

2.13. Conclusion

This chapter discussed the challenges experienced by the PLWHIV on the termination of their temporary disability grants. Different models were used to describe disability. The chapter also reviewed the Policy on the application and awarding of the temporary disability grant. The study was guided by the Theory of Social Capital and HBM. These theoretical frameworks were used because they support the importance of social networks in the survival of PLWHIV. The HBM argues that it is important how one perceives the benefits of action, and the obstacles to action. Self-efficacy can help in improving their health. The following chapter will discuss the methodology of the study.

CHAPTER 3: Research methodology

3.1. Introduction

The chapter describes the research methodology and research design used in the study. The qualitative methodology was used with exploratory design. Methodology is regarded as a broad approach a researcher uses to examine the research problem. The reason for using qualitative methodology is because this approach is appropriate when used to explore complex issues (Wright, McSweeney, Frith, Stewart & Booth (2009:120). As Ragin (1994:43), argues, the objective of this kind of study is to tell the story of people living with HIV in a way that enhances its visibility in the society. It is believed that the Temporary Disability Grant was a lifesaving means for the people who were not working and living with HIV, hence a qualitative methodology was used to explore the challenges experienced by PLWHIV on the termination of the Temporary Disability Grant (Manuela de Paoli, Mills & Grønningsæter 2012:4). For research design, exploratory design was used.

This chapter covers the research design, sources of data, sampling technique, data collection process, data analysis as well as the ethical considerations undertaken during the research.

3.2. Research Design

Research design is described as the organised framework that the researcher is using in order to conduct the research process so as to solve the research problem (Kumar 2014:123; Babbie 2011:103). Exploratory design was used to explore the challenges experienced by PLWHIV when their Temporary Disability Grants were terminated. An exploratory study helps to determine the best data collection method and selection of subjects (Braum & Clarke 2013:79). This type of study can be used because the researcher anticipated having to explore societal issues like the challenges experienced by PLWHIV when their Temporary Disability Grants were terminated (Babbie 2013:90; Neumann & De Freitas, 2009:1).

3.3. Study area and context

Ekupholeni Mental Health and Trauma Centre is non-governmental organisation dealing with people from disadvantaged background. These people include children and adults who are infected and affected by HIV and AIDS. The centre provides

services also to delinquent children and orphans. It serves people speaking both Zulu and Southern Sotho. The centre is situated at Natalspruit hospital in Katlehong. Katlehong hosts about 407,294 inhabitants. Katlehong is a township located 35 km east of Johannesburg and south of Germiston with a density of 7,400/km2. Its racial composition consists of 98.4% of Black Africans, Coloureds, 0.5% and Indian/Asians, 0.8% (Census, 2011).

Katlehong Township has a high level of unemployment. Katlehong is one of the poorly served areas in Gauteng in terms of community development. Thokoza and Vosloorus form the second biggest black township after Soweto. The participants of the study were members of the support group formed by the centre for PLWHIV. The participants were recruited by the researcher with the help of the support group caretaker and the chairperson of the support group.

3.4. Sample

The sample was a group of people about whom the researcher wanted to draw conclusions (Babbie 2011:166). The study sample consisted of PLWHIV who were members of the support group, who were receiving temporary disability grants and they experienced termination of their grants. Nine participants were recruited and interviewed.

3.5. Sampling Technique

Sampling technique is the method used by the researcher to choose the participants from the population (Babbie 2011:187). For this research, the purposive sampling technique was used to choose the participants from the population. The participants were comprise of PLWHIV and receiving temporary disability grants, and those who had experienced the termination of disability grants. The reason was that; due to the termination of their temporary disability grant, they were more exposed to poverty and the risk of poor management of the disease. The researcher excluded those who had not received the grant.

The importance of purposive sampling is that it is economical and less time consuming as the researcher can reach the targeted sample quickly. It allows researchers to select a sample based on the knowledge of the population purpose of the study (Babbie 2013:129; Braum & Clarke 2014:59; Okeke & van Wyk 2015: 225). For this study, the researcher conducted purposive sampling by firstly visiting Ekupholeni

Mental Health and Trauma Centre to learn about different services the centre provides to PLWHIV and other people in need, such as orphans. The chairperson of the group informed the participants about the interest of the researcher on recruiting participants to partake in the study. Second, the researcher enquired whether or not PLWHIV were receiving the temporary disability grant. Last the researcher wrote a letter to the centre asking for a permission to conduct the study with PLWHIV who were part of the people served by the centre. The letters written in this connection can be seen in appendix A.

3.6. Pilot Study

An additional five participants were recruited for piloting the interview schedule. They were not part of the study to avoid pre-intended answers as they would be accustomed to the questions. The pilot study showed no ambiguous or double-barrel questions and all the participants understood the questions in the same way. The reason for piloting the interview schedules was to guarantee the trustworthiness of the study, to ensure the consistency in the interpretation of the questions, to rule out the ambiguous questions in the interview schedule (Babbie 2013:108).

3.7. Sources of Data

Sources of data are the material used to collect data (Blaxter, Hughes & Tight 1998:143). There are different kinds of data sources, namely primary and secondary source of data. For this study, the primary source of data was used. The importance of primary data was that the researchers are collecting information for the specific purposes of their study. In essence, the questions the researchers asked were structured to produce the data that will help them with their study (Blatex, Hughes &Tight, 1998:143). Data was collected using in-depth interviews technique.

3.8. Data Collection Technique

Data collection technique is a method used by the researcher to collect data (Babbie 2011:40). The technique that was used is the in-depth interview using an interview guide (Appendix B). In-depth interviewing is a qualitative research technique that encompasses conducting intensive individual interviews with a small number of respondents to explore their understanding of the termination of the temporary disability grant (Babbie 2011:40). The in-depth interviews were helpful when the researcher needed thorough information about the PLWHIV's thoughts and behaviours when their Temporary Disability Grants were terminated.

The importance of using the in-depth interview is that it is normally provides rich and comprehensive data with new insights. Also, the in-depth interview's greater flexibility allows in-depth exploration of the answers and that can lessen the errors of misinterpretation and misrepresentation (Hofisi, Hofisi & Mago 2014:62; Okeke & van Wyk 2015:299). This is important because the researcher wants to collect information that is relevant to the study topic.

When collecting the data, the researcher visited support group of PLWHIV at Ekupholeni Mental Health and Trauma Centre. The support group was formed by this centre. The support group was meant for PLWHIV to meet to discuss and advise each other on the daily issues that were affecting them in relation to HIV and AIDS. The other reason for the visit was to establish a rapport with the study group. The visit took place when the group members (Siyanqoba) came for their weekly meetings. The researcher was given time to meet the participants and to explain the purpose of the research, to find out if they were interested in participating and also to know what they were expecting from the study.

With the permission of the director of the organization and chairperson responsible for the group, the researcher made an appointment for an actual interview which was at their next group meeting that was held every week. The targeted number of participants was 10 and 9 participants were interviewed, 8 women and 1 man. The interview took 45-60 minutes with each interviewee. The interview guide was translated into Zulu and was facilitated in Zulu to give participants freedom to express themselves easily. Giving participants the freedom to use their home language enhanced the data because their hidden perspectives about the challenges and effects of termination of the Temporary Disability Grant in their lives emerged. The data was then translated into English for data analysis. (See the letter asking for permission in appendix A.)

Furthermore, information on their age, marriage status, level of education, employment status and number of the children they had and also if they owned or rented the houses they were living in were asked. The reason for including this information was to understand the socio-economic backgrounds of participants.

3.8.1. Data saturation

Data saturation is reached when there is sufficient information to replicate the study, when the ability to get additional new information has been achieved, and when further coding is no longer possible (Fusch & Ness 2015:2). To achieve data saturation, the researcher chooses data collection methodology that has been used before. In-depth interview was used and it demonstrated that data saturation had been reached when it was used (Fusch & Ness 2015:3). The data saturation was reached when the researcher reached basis of the data that have been collected needed no further data collection and when she realised that she could not get any new information form the interview she conducted.

3.9. Validation

3.9.1. Trustworthiness

Trustworthiness is one way researchers can persuade themselves and readers that their research findings are worthy of attention (Lincoln and Guba (1985), stated in (Babbie 2011:129). The trustworthiness of the study was addressed through translating the interview guide from English to Zulu. That was done because the researcher wanted the participants to understand thoroughly what they were asked so that they could give valid answers. The Zulu data was translated back to English for transcribing. Credibility, transferability, dependability and conformability, according to Lincoln and Guba (1985), were used to ensure trustworthiness of the study as explained below.

3.9.1.1. Credibility

Credibility refers to how congruent the findings are with reality. Lincoln and Guba (1998) claimed that ensuring credibility is one of most important factors in establishing trustworthiness (Shenton 2004:2). The credibility was ensured by the following steps: First, the participants were allowed to share their experiences on the termination of Temporary Disability Grant using their own vernacular which was Zulu without being judged. Second, the researcher attempted to establish a good relationship with the participants by visiting the support group before she could conduct the study. The good relationship was meant to help participants to respond freely about their experiences during the interviews. Thirdly, the in-depth interviews were translated back to English and transcribed verbatim and field notes were further reviewed to ensure that non-

verbal information was not lost but integrated into the data. Last, an interview guide was compiled after being piloted and used throughout the study to ensure standardization and consistency across interviews with participants.

3.9.1.2. Transferability

Transferability refers to the concern with the extent to which the findings of one study can be applied to other situations, or the extent to which the results can be transferred to other settings (Shenton 2004:7). To ensure transferability, the researcher provided in the report, the aims, objectives, research design and methods including the demographic characteristics of the participants and research findings. The data were also kept in a secured place for future cross checking or verification and that was done to ensure that the raw data would be available if needed.

3.9.1.3. Conformability

Conformability is the degree to which the results of an inquiry could be confirmed. It ensures that the findings, data and interpretation are not for the personal interest of the researcher (Anney 2014:279). To reach conformability, the researcher recruited the services of another researcher who was not part of this study to check for the authenticity of the research findings. Discussion of data analysis will follow.

3.10. Data Analysis

Data analysis is known as a paradigm and theoretical style the researcher uses to ascertain the answer to her question (Babbie 2011:491). For data analysis and interpretations, the researcher recorded the interviews so as to allow thorough examination of what the participants had to say. The transcripts were compared by the interviewer to verify accuracy (Marshall & Rossman 1999:108; Wright *et al* 2009:160). The data was transcribed for analysis and interpretation.

Thematic analysis was used to analyse the data. Thematic analysis is defined as identifying, analysing and reporting themes within data. It interprets various aspects of the research topic through themes. A theme captures something significant about the data in relation to the research question and represents some level of patterned response, or meaning within the data set.

To analyse the data using thematic analysis, the researcher followed the following steps by Braum & Clarke (2013).

3.10.1. Familiarising oneself with your data

To familiarise herself with the data, the researcher immediately transcribed the voice data from the tape recorder and put it into a written form herself. The researcher continued to read and re-read the transcribed data. While reading, she was looking for the meanings and patterns and also taking notes on the initial ideas before she could code it.

3.10.2. Generating initial codes

The researcher generated codes by identifying preliminary codes. The preliminary codes were the features of the data that appeared interesting and meaningful in the study on the challenges experienced by PLWHIV on the termination of the Temporary Disability Grant. The researcher ensured that the codes were related to the objectives of the study.

3.10.3. Searching for the meaning

The researcher read the data carefully to find the significant segment of the text in a transcript. After she found the meaning, the researcher assigned a code for that meaning. She focused on the wider level of themes and she sorted different codes into potential themes that will answer the research questions.

3.10.4. Reviewing themes

At this stage, the researcher defined the existing themes and refined them so that they could be obtainable in the final analysis. She re-read all the data extracts that fitted into each theme to confirm that all of her data forms a clear pattern. She confirmed that data within themes cohered together meaningfully and that there were clear and identifiable distinctions between themes by using a thematic map to help her to visualize the relationship between the themes.

3.10.5. Defining and naming themes

The researcher refined and defined the themes and potential subthemes within the data and provided themes with names and clear working definitions. She did this by generating an overall narrative with all of her data and analysed each theme and its individual narrative.

3.10.6. Producing the report

Finally, the researcher changed her analysis into an interpretable piece of writing by using extract examples from the in-depth interviews that relate to the themes, research

question, and literature from the data. The researcher reported the results of the analysis in a way that convinced the reader about the merit and validity of the analysis.

Thematic data analysis employed different stages that were important in establishing the data that was making sense and giving answers to the study questions. Apart from that, coding and extracting themes from the data was done by using thematic data analysis. The discussion on ethical considerations will be next.

3.11. Ethical Consideration

Ethical considerations were applied in the evaluation of what should be done or what should not be done when conducting a study (Kumar 2014:285). The UNISA ethical approval was awarded to the researcher after submitting research proposal together with a letter from the centre that allows her to conduct the study. To ensure the ethical conduct of the study, the rights to voluntary participation, anonymity, confidentiality, privacy and informed consent were observed (Babbie 2013:33).

3.11.1. Voluntary participation

The ethical principle of voluntary participation was also maintained. The participants decided to participate on their own without being influenced by the researcher. The participants were treated as independent agents by informing them about the study and letting them willingly choose to participate or not (Christensen, Johnson & Turner 2011:105; UNISA 2016:13). Participants' consent was obtained before they were enrolled into the interview (Babbie 2013:35). That was done by informing participants about the contents of the study, their rights to freely consent or decline to participate, and to withdraw participation at any time without penalty (UNISA 2016:16). If the participants of the research study were children, meaning any person under that age of 18, the parent or guardian had to consent on behalf of the child (Department of Social Development 2007:4).

3.11.2. Anonymity

Anonymity was defined as when participants cannot be connected, even by the researcher, with his or her individual responses. Anonymity permits participants free expression of their views (Okeke & van Wyk 2015:378). To ensure Anonymity, the researcher asked the participants to use pseudo names instead of their real names, the names and ages of the participants were removed from the research report (Christensen, Johnson & Turner 2011:105).

3.11.3. Confidentiality

The confidentiality of data was upheld by keeping the collected data confidential. This was done by taking the following steps: The information was not used or published in a form in which the individuals could be identified, the researchers took sensible technical and operational measures to guarantee that research records were stored in such a manner as to protect confidentiality. The researcher created a code to the folder that had the data and records of participants. The participants were made not identifiable in the report, hence “participant A” was used instead of using their gender and age, finally no identifying information was audio taped.

3.11.4. Permission to conduct the research study

The permission to conduct the research study was obtained from the Department of Sociology Research Committee at UNISA by issuing the ethical clearance to the researcher. Ekupholeni Mental Health Centre also issued a permission letter. Apart from that, the participant’s informed consent was obtained before they participated in the study. For the university’s ethical clearance, see Appendix D. For the permission letter, see Appendix A.

3.11.5. Informed consent

Informed consent is defined by Wagner, Kawalich & Garner (2012:86) as the subject's agreement to partake willingly in a study. The informed consent was reached after absorption of crucial information about the study. To reach the informed consent, the researcher explained to the participants that they have rights to voluntarily consent or decline to participate, and to withdraw participation at any time without penalty. Moreover, the participants were informed about the purpose of the study and that the study will be covering information like the age of the participants and their marital status, and also that audio taping would be used to collect the data. Also, the participants were assured there were no potential risks or costs involved when one is taking part in the study. For the informed consent form, see Appendix C.

3.11.6. Privacy

To ensure that the participant’s privacy is protected, the researcher was introduced to the participants by the chairperson of the group. The participants were in their room where there was no one else to listen to the conversation except the researcher. The chairperson of the group left the group after introducing them to the researcher. That

was done because the study involves HIV which was considered to be a sensitive issue and to prevent any discrimination that could be imposed on the participants by the onlookers. Each interview was recorded and it was a one-on-one interview.

3.11.7. Risk and protection

The study did not pose any risk and adverse consequences because all recruited participants had the same characteristics, meaning they were all diagnosed with HIV and they were receiving, or had received the Temporary Disability Grant. However, the researcher conducted the in-depth interviews in a private room where it was a one-one-one session with the participant.

3.11.8. Debriefing

To debrief the participants, the researcher fully informed the study participants about the actual nature of the study and allowed participants to ask questions and discuss any concerns that they might have had. The participants were informed that they would get psychosocial support from the centre should they experience any unpleasant consequences as a result of the study.

3.12. Conclusion

This chapter described the methodology and the design that were employed by the study. The study used a qualitative research methodology and followed an exploratory research design. The chapter also defined the data collection tools and the process of the data collection. In addition, the chapter described the ethical considerations employed by the study as well as the data analysis process that was employed by the study. The following chapter will discuss the findings of the study.

Chapter 4: Findings

4.1. Introduction

This chapter discusses the findings of the qualitative study on the challenges experienced by the people living with HIV on the termination of the Temporary Disability Grant. This chapter follows a thematic analysis which was used in processing, describing and discussing themes that emerged from the in-depth interviews with the participants as described in the previous chapter. This chapter will discuss the overall finding of the study which includes biographical profiles of the participants and the challenges faced by PLWHIV after losing the disability grant.

The analysis was made using the objectives of the study which were: To explore the challenges experienced by PLWHIV after losing the Temporary Disability Grant, to discover the effects of the termination of these grants on the lives of PLWHIV, to explore the importance and the contribution of the Temporary Disability Grants (TDG) to the lives of PLWHIV and to investigate if increasing the time frame for receiving the temporary disability grant can help to address the challenges caused by the termination of the grant.

4.2. Biographical profiles of participants interviewed

Participant	Age	Gender	total number of children	total number of household members	employment status
A	35	Female	4	6	Unemployed
B	37	Female	3	5	Unemployed
C	36	Female	2	4	Unemployed
D	46	Female	7	8	Unemployed
E	53	Female	5	6	Unemployed
F	43	Female	4	5	Unemployed
G	40	Female	4	5	Unemployed
H	35	Female	2	3	Unemployed
I	45	Male	5	7	Unemployed

Participant's ages ranged from 35 to 53, 53 being the eldest while 35 was the youngest. The ages of participants helped with knowing if the participants were in the working age range (SASSA 2016:3). All the participants that were interviewed were unemployed. The importance of the participant's employment status was to affirm that the recipients were qualified for the disability grant. The smallest household size comprised of four members and the largest household had seven members. The importance of the participant's household size was to support the notion that the disability grant is very important to the grant recipients as it supports many people who are the responsibility of each of the grant recipients.

4.3. Overall findings of the study:

The findings of the study are presented through extracting the themes from the data based on the objectives of the study as well as some emerging themes.

4.3.1. The challenges faced by PLWHIV after losing the disability grant

During the interviews, the participants were asked what challenges they were facing when their disability grants were terminated. Most of the participants articulated the challenges of terminating temporary disability grant as the cause of more problems in their lives. Economic challenges and physical challenges were themes found among the challenges PLWHIV experienced when their disability grants were terminated (Kgaee 2014:2).

4.3.1.1. Economic challenge

The fall of household income when the disability grants are terminated was used to show that the PLWHIV are living in poverty and the termination of the Temporary Disability Grant worsens the situation. The research conducted by Kagee (2014) on 'Do disability grants influence adherence to antiretroviral therapy?' which stated that poverty intensifies the likelihood of a high disease burden in a society, and disease in turn aggravates poverty, supported the findings of this study. Most of the participants agreed that they felt the pinch of poverty mostly when their Temporary Disability Grants were terminated.

When interviewed, most of the participants revealed that they were struggling to get a job as they were too weak to go "market" and others had to leave their jobs because their bodies were getting weak because of disease so much that they could not work anymore. Apart from that, most of the participants mentioned that the lack of a job was

posing a serious challenge to them and their families as they cannot afford to take care of themselves and their family members.

> *"And if I eat, what children will eat because I am not working (frowning facial expression) do you see that? I am not working even their father is not working. I depend on their grant money". Participant A.*

> *"I am taking pills and I am not working and my husband is not working". Participant C.*

> *"My children are having children and I am not working". Participant E.*

When asked about the problems posed by their struggling to get job, they mentioned problems like not being able to buy the household necessities coupled with not being able to pay for the children's school fees. Not receiving the money poses financial barriers which affects school attendance together with difficulties to purchase school supplies like uniforms and to pay tuition fee and transportation (Gurura & Tanga, 2014:667).

> *"And me too I can also look for a job because when you go to market (look for job), you need money for transport*". *Participant C.*

> *"Now I am stressed that my children have no clothes for Christmas. The other child who is going to be 14 has to go for graduation on the 5th". Participant E.*

> *"I cannot buy them because I am not working. We're told to eat healthy food, where will I get them. I got scarred when I was told that my cd4 count is 79, and they said I should eat healthy staff". Participant A.*

> *"The two are in grade 6 and 11, the other one is in grade 1 and is 6 years. The other one who is my sister child is in grade 11 and her mother passed on, I will be paying for their school fees". Participant G.*

Running the household without money posed challenges as the PLWHIV were not surviving without their temporary disability grants. The following sub-themes explain the economic effects the PLWHIV experienced when their disability grants were terminated.

4.3.1.1.1. Lack of financial support from partners

Lack of money was the notion that came up during the interviews. Some participants who were staying with partners or spouses reported that their husbands did not want to contribute money to help with the running of the household. That happened even when their husbands were working, they did not want to give their wives money to support the families. When they were asked if this stingy issue came after or before the participants received their disability grant, most of the participants stated that it happened after they received their grant.

> *"I have stress and my partner is very stingy. I'm stressed, they went away on Friday and came back on Saturday for a farewell. I wanted to try to pay for him for graduation." Participant B.*

> *"My husband does not care for me. He leaves in the morning and at night". Participant C.*

Even though most of the participants were seeing the disability grant as the most important thing that had happened to them, when interviewed, some participants were complaining that the money does not cover most of their needs. They reported that the money they received is only for buying maize-meal for making pap and nothing more.

> *"It is not the same… though is it too small (not enough) I am trying to buy for children…I have to buy food for 3 children and it is not enough. I try to get clothes also. It does not cover everything at home because the children are not working". Participant D*

> *"I have covered all my children with that money. It is very small. No one is helping me". Participant H*

Having a little income is better than having nothing at all. Although the money is insufficient, the PLWHIV can cover at least some of the necessities.

4.3.1.1.2. Scarcity of food before taking treatment

Scarcity of food was another economic effect PLWHIV experienced when their Temporary Disability Grants were terminated. Most of the participants alluded to the fact that there were times when the participants could not take treatment because they did not have food. Most of the participants reported that taking treatment on an empty stomach was hurting them so much that they could not bear the pain hence they tended to skip taking treatment and that was not good because it was not the way they were supposed to take medication.

> *"These pills I am supposed to take with food, it is problematic and sometimes I get dizzy. It's as if one can eat frequently, and if I eat, what children will eat because I am not working (frowning facial expression)". Participant A.*

> *"I am the person that has no energy (weak). The pills are hurting me if I take them without food". Participant D.*

Taking medication requires that one has to have food, otherwise they resort to not taking the medication accordingly.

When probing, it emerged that the termination of the Temporary Disability Grant had contributed to participants skipping the treatment because they did not have money to buy food that they needed to eat before they took the treatment. These findings are supported by the study conducted by Azia, Mukumbang and van Wyk (2016), on 'Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa', stating that the issues interfering with their inability to take ART as prescribed were poverty and unemployment, lack of money for transport, and lack of food.

4.3.1.2. Physical challenges

Another challenge posed by the termination of temporary disability grand was on physical being of the recipients. The sub-themes that emerged under this theme were Non-adherence and Wellness of the participants.

4.3.1.2.1. Non-adherence

When interviewed most of the participant revealed that they understood what was non-adherence all about. Most of the participants uttered that non-adherence is when one

is not taking the treatment as prescribed. Most participants reported that non-adherence may lead to one getting to the AIDS stage and dying. Most of them continued saying when one is not taking medication in the proper manner that can lead to mismanagement of the disease which in turn can result in getting to the AIDS stage and viral rebound. When they were asked about what caused them not to adhere to the treatment, most of them reported that lack of food was the source.

Participant F, who lives with three children reported that she skipped treatment when she did not have food. The reason was that the pain caused by the treatment when taken on an empty stomach is unbearable. This was also further explained by other participants.

> *"You cannot take treatment skipping days because today you have food and tomorrow you don't, you cannot do that to the treatment. That's all. Thank you." Participant C.*

> *"The grant helps me to buy food because the pills are hurting me seriously and I lose energy" Participant D*

> *"Yesterday and today I did not take my pills because I don't have food…I have not taken my pills (wiping the tears)." Participant E.*

> *"I don't have food and the pills are hurting me if I take them without food. Sometimes I end up not taking them because they hurt me when I take them without food. I drink HIV pills". Participant F.*

> *"No food at home. I just took the pill for pain only. And this one you just put it in the boiling water and I drank that one. The reason being that there is no food at home." Participant E.*

Their concern was that they were not taking the treatment the way they were supposed to because the ARVs were hurting them when taken without food. As much as they knew about the consequences of not taking the treatment accordingly, their immediate concern was to avoid the pain that would be caused by taking treatment on an empty stomach.

4.3.1.2.2. Wellness of the participants

Wellness of the participants was the sub-theme found when probing about the physical effects resulted from termination of Temporary Disability Grant. During the interview, most of the participants reported their wellness in regard to gaining body weight and looking healthy. Meaning that if they do not take medication as prescribed they tend to lose weight and look sick.

> *"I took blood last month when I went to the clinic to fetch the tablets, it was on the 7th. But this month they asked me why my blood is up (cd4 count) like this". Participant B.*
>
> *"My life…(wipping tears from eyes) my cd4 count was very low.. My cd4 count was not improving". Participant D.*
>
> *"It's very difficult, and now that I am not taking pills. Last month I went to test for the cd4 count, they told me that my cd4 count does not improve. They asked me lot of things. I told them that I take my pills without food and apart from that I have stress". Participant H.*
>
> *"Now I am sick, its diabetes, high blood, and asthma everything is up". Participant E*

The participants were asked about how they used money in order to sustain wellness. Most of them further explained that when they had money they received in the form of a Temporary Disability Grant, they were able to buy nutritious food like vegetables and fruits that were contributing and helping their bodies to gain weight and contributing to building the strong immune system and thus improving the CD4 count.

They reported struggling to sustain good health and wellness, as they could not afford to buy food. These results are supported by the study that was done by Manueal de Paoli *et al* (2012:3) on 'The ARV roll out and the disability grant: a South African dilemma?', This study concluded that the loss of income when disability grants are not renewed had a substantial implication on both the individual living with HIV and the wellness of the household.

4.3.2. The effects of the termination of disability grants on the lives of PLWHIV

The termination of the Temporary Disability Grant did not only negatively affect its recipients but also other family members such as the children of the recipients. This was described when the participants were asked about what consequences were brought into their lives by the termination of disability grants. Social effects, poor management of HIV and AIDS by PLWHIV, Challenge of facing the sickness, Disappointment when renewing disability grant and Poor administration by the offices that deal with the renewal of disability grants

4.3.2.1. Social effects

Most of participants reported that they could no longer take their children to school. The reason was that they had used the money they received as the Temporary Disability Grant to pay for the school fees and to buy stationery for their children. Most of them also reported that the termination of the Temporary Disability Grant had negative effects on the lives of the disability grant recipients. This had contributed to more problems when it came to supporting the family, especially children (Gutura & Tanga 2014:667)

> *"The child that is in grade 11. I can be able to save money for him for university". Participant C.*

> *"Even now I am stressed that my children have no clothes for Christmas. The other child who is going to be 14 has to go for graduation on the 5th".Participant B.*

> *"Help my child who is at the college who is 22 years. I don't have money for his fees and transport. But I want him to be educated". Participant F.*

When more probing was done, most participants shown that not only school fees of their children was affected by termination of Temporary Disability Grant, however the wellbeing of their children was also affected. Participants claimed that they were struggling to buy their children new clothes for Christmas.

> *"Now I am stressed that my children have no clothes for Christmas. Participant B*

During probing, it emerged that the consequences of the termination of the disability grant will have long term effects on the lives of the children of Temporary Disability Grant recipients. One of the participants reported that “our children will not be able to go to school and their children will also not be able to go to school and the situation will not change in their lives”. That point was also supported by the views of other participants when they mentioned that their children were not working and there was no one to help them when their disability grants were terminated. That might be due to the fact that there was no money to take them to school or they had to look after their sick parents, and so they were unable to work.

> *“It will help me to take my children to school because I am not working. It can help me with many things like the child that is in grade 11. I can be able to save money for him for university. And me too I can also look for a job because when you go to market (look for job), you need money for transport.” Participant C.*
>
> *“It can buy children Vaseline, they can bath and eat after school and there will be life in the house. Yes, if you don’t get its obvious!” Participant A.*

Receiving Temporary Disability Grant does not only benefit its recipients but also their children. Not being able to take children to school threatens the future of PLWHIV’s children. Children of the PLWHIV are not enjoying Christmas holidays like other children, the reason being that their parents cannot afford to entertain them due to lack of finances which happens when their temporary disability grants are terminated.

4.3.2.2. Poor management of HIV and AIDS by PLWHIV

As probing continued, participants were asked what about the effects of the termination of the temporary disability grant. Most of the participants reported that they stopped taking treatment because they could not afford to buy food. That was what made them to stop taking treatment. That was also seen as the contributor to poor management of HIV and AIDS by PLWHIV.

As probing continued, most of the participants raised the idea of poor management as a result that came with the skipping and not taking the treatment as directed by the health practitioners. When they were asked about how the availability of food had anything to do with the poor management of HIV and AIDS, most of them cited what

they were taught at the clinic before and after they could start with their treatment that they needed to eat healthy food so that the treatment can work. They proceeded to say that the information they were given included resistance of the ARVs to treat them if they were not eating well. And that would lead to a deteriorating immune system that would make them even sicker.

> *"You know what? I am stressed. I took blood last month when I went to the clinic to fetch the tablets, it was on the 7th. But this month they asked me why my blood is up (cd4 count) like this. They asked me if I am using condoms.'' Participant B.*

> *"It because sometimes I stop taking pills because I see there is no difference. But sometimes I see that I am killing myself because I have children". Participant A.*

> *"It's very difficult, and now that I am taking pills. Last month I went to test for the cd4 count, they told me that my cd4 count does not improve. I told them that I take my pills without food and apart from that I have stress". Participant H*

> *"You cannot take treatment skipping days because today you have food and tomorrow you don't, you cannot do that to the treatment'. Participant C.*

Some participants mentioned that taking the medication as they were taught made them not to fall sick frequently.

> *"I have not been sick since I take pills, they are treating me very well, but they do not want hunger, they need you to eat. If you eat them without food is not right." Participant D*.

As the interview continued, poor management of HIV and AIDS was also seen when most of the participants indicated that they could not afford to go to the clinic to fetch their medication. That was because most of them did not have money for transport. They ended up defaulting from the treatment as they lacked money for transport. As a result, days could pass without one being able to find the money for transport.

"We really need the government. It should seriously help us. You cannot take treatment skipping days because today you have food and tomorrow you don't… you cannot do that to the treatment. That's all. Thank you." Participant C.

"I used to borrow money from other people for transport" Participant E

The termination of disability grants affects proper management of HIV and AIDS and it also causes PLWHIV to stop taking medication accordingly.

4.3.2.3. Challenge of facing the sickness

Through the interview, the participants were asked about other outcomes on their lives that were brought about by the termination of their Temporary Disability Grants. Most of the participants alluded to the fact that experiencing termination of the disability grant and being diagnosed with HIV did not only pose the challenge of facing the chronic sickness, but knowing that they will never be healed from HIV no matter how they treat it contributed to sickness and endless stress. The stress was also due to the fact that the Temporary Disability Grant had to be terminated at some time. When probing was done around the issue of knowing that they will not be healed and that was related to stress, most of the participants raised the issue of scarce jobs and their weak bodies that cannot carry them to go and look for a job. Most of the participants went on to report that the higher the stress level, then the higher was the viral load. The viral load was reported to be leading to the low immune system.

"Last month I went to test for the cd4 count, they told me that my cd4 count does not improve and I have stress. I have stress about children. And if you are sick you have to be ok because if you are stress you become even sicker". Participant G.

''We're told to eat healthy food, where will I get them. I got scared when I was told that my cd4 count is 79, and they said I should eat healthy stuff'' Participant A

Facing the opportunistic diseases was a worrying issue that might be a result of the termination of the Temporary Disability Grant.

4.3.2.4. Disappointment when renewing disability grant

When being asked about other effects of the termination of the Temporary Disability Grant, most of the participants reported disappointment when they had to renew their disability grants. They were disappointed by the struggles they had to go through for their grants to be renewed. Stated a 53-year-old woman who reported that she was returned from SASSA several times:

> *"They said my application was not received and they said I should go home and come after 3 months. I end up giving up." Participant G.*

> *"Six months all going from 7-7 going there. Even now I am thinking of going back". Participant E*

During the interview, most of the participants stated that renewing the disability grant was a nightmare. That was illustrated by how many times one had to go to the SASSA office for the renewal of the grant. "There was a guarantee that for the grant to be renewed one had to visit SASSA offices many times and that also affected us negatively as we were using money we did not have". Those were the words of the 53-year-old woman when expressing her experience when she went to renew her disability grant. Other participants mentioned that unclear instructions given by the nurses made them struggle to renew their grant. Most of the participants reported that they were just told to go to SASSA, but proper guidance on what to do when one gets there was lacking.

> *"I did receive it when I started to get sick, it was long time ago, many years ago when I started to take pills. I had it for six months. They then close it. They told me to renew it. I have been there to renew renew renew renew and it failed." Participant E.*

Above that, being turned down was another issue that the participants raised during the interview. Most of the participants stated that being turned down at the clinic was another struggle they faced when they went to renew their disability grant. When the interviewer probed around the concept of being turned down, it was revealed that for one to end up renewing the grant, one must be turned down several times. Most of the participants cited that they had to go to SASSA more than 5 times and others ended up losing hope and stopped trying to renew their disability grants.

The 53-year-old woman reported going to SASSA, for the renewal of her disability grant so many times that she could not remember. She would be turned down and so many times she was told to come back next week.

> *"Six months all going from 7-7 going there. Even now I am thinking of going back. They told me to renew it." Participant E.*

> *"The situation is bad, very bad. I spent that year trying to renew, but still the same, it fails again. Yooooh. They told me not to come again". Participant H*

Another effects of termination of temporary disability grant was when participants had to go to SASSA offices several times without being helped.

4.3.2.5. Poor administration by the offices that deal with the renewal of disability grants

When the participants were asked to elaborate on their struggles to renew their disability grant, most of them reported unclear written down procedure to follow when renewing the grant and poor sharing of the information by the health professionals that the Temporary Disability Grant will be terminated after six months of receiving it. When probing around the issue of procedure to be followed when renewing the grant, most of the participants reported that it would help if the clinic could tell them in advance what they should bring when they went for renewal, how long they should wait to get the feedback of their application and which offices they should go to, renewal would not be that complicated.

When probing was done, poor sharing of information was recognised from what other participants were saying. The 47-year-old participant reported that she was told to go and renew her disability grant, but it seemed like she was not told about the duration of the allocation of receiving the grant. She just got bad news of it being terminated when she went and inquired after she could not receive her money. Most of the participants suggested that at least if they could be told about the dates when their disability grant will be terminated, that would give them the chance to prepare for the bad news and try other means of getting money. Miscommunication between healthcare professionals and services users appear to be an everyday issue that confirms poor administration by the health providers (Govender *et al*, 2015:8).

"They said I should take it to SASSA. There at SASSA I got problems. They completed the forms very well but when I come to Tsotetsi to sign, then I met the problems. He came telling me that he does not take paper from Ekupholeni. He does not work with social workers from Ekupholeni. He told me to bring the paper of water (municipality bill statement)." Participant E.

"They will tell you that it has been stopped, then they will tell to go and renew it". Participant C.

"It happen that it can be closed after 6 months or a year." Participant G.

When the grant is terminated, renewing it also poses problems that are caused by poor administration from the offices that issue the disability grants. These findings resemble the one of the study conducted by Kelly (2013), on 'regulating access to the disability grant in South Africa, 1990-2013'. That study reported that the inefficiencies by the administrative staff presented a serious barrier to accessing the grant. Grant receivers reported that the application process was frustrating and complex and for their application to succeed depends on how lucky one is to find a sympathetic official.

4.3.3. Importance and the contribution of the Temporary Disability Grants (TDG) in the lives of PLWHIV

The third objective of the project was exploring the importance and contribution the disability grants make in the lives of people living with PLWHIV. During the interview, the biographical information of the participants revealed that none of the participants that were interviewed were employed. Most of the participants reported that they could only do odd jobs, like doing washing for another person so that they can be paid. For that reason, the disability grant serves as their source of money when those odd jobs were not available. When probing about only doing the odd jobs, they claimed that the reason was that they were not educated and only odd jobs were available for them. The following are the themes on importance and the contribution of the Temporary Disability Grants (TDG) in the lives of PLWHIV.

4.3.3.1. Social relationships

When interviewed, most of the participants stated that Temporary Disability Grant had contributed positively to their social relationship with other family members and their

neighbours. They continued to show that due to the lack of job opportunities which had contributed to loss or no money in the family, the availability of the Temporary Disability Grant had contributed positively to the relationship with the neighbours. The participants reported that they did not have to borrow money from the neighbours or ask for some food, which was found to have irritated their neighbours. Kagee (2014:3) maintained that health improvement and maintenance permit patients to depend less on others, thus protecting Social Capital.

When the interview around the importance of Temporary Disability Grant was taking place, most of the participants revealed that the grant contributed to less trouble with asking for help from the neighbours. “The relationship with the neighbours is sometimes messed up by the burden other neighbours put on their neighbours” cited participant A. When participants were asked about the other importance of the disability grant in their lives, most of the participants mentioned that they shared the money they received as disability grant with other relatives excluding her children to take care of their needs.

> *“You think they can help us because we are struggling, there are no jobs. The neighbour cannot give you mealy-meal every day. You have to go and do someone’s laundry so that you can get R50.00 to buy maize-meal without any ‘seshabo’.” Participant A.*

During probing on other important aspects of the temporary disability grant, most of the participants mentioned that they also take care of the neighbours with the money they receive as the disability grant. Although the money that people living with HIV received was meant strictly to help the recipients, due to the poverty the community is facing, even the neighbours of the disability grant recipients did benefit from it.

> *“Sometimes if you go and see someone, if he/she has nothing, you can cook porridge for her. But if you have nothing, you cannot because you struggle to get maize-meal too. People are struggling, and people are dying too.” Participant A.*

> *“It helps a lot because some families are surviving because of it. If it was not because of it, there would be only tombs” added Participant A.*

Being able to use Temporary Disability Grant on people other than the recipients of the disability grant showed how important it is in the lives of PLWHIV and the people surrounding them.

4.3.3.2. Empowerment and adherence

During the interviews, empowerment and adherence were what emerged from most of the participants as another theme that supported the importance of the disability grant. The importance was seen through the ability to send children to school and pay for the children's school fees and to take care of funeral policies. From the study conducted by Gutura and Tanga (2014) on Social grants and the intended consequences: Is South Africa there yet, revealed that the social grants has enhanced the lives of the children by providing them with the opportunity to attend crèche or school, that is through being able to pay school fees and buying school uniforms (Gutura & Tanga 2014:667).

When probing about the empowerment, most of the participants mentioned that ability to plan and budget using the disability grant has empowered them to be like other people. They were able to buy clothes so that they can look good when they were around other people.

Moreover, the empowerment was seen through their ability to live normally like other people who are not regarded as being disabled due to illness.

> *"It will help me to take my children to school because I am able to save money for him for not working. It can help me with many things like the child that is in grade 11. I can be able to save money for their university" Participant C.*

As probing continues on the importance of the disability grant in their lives, other participants claimed that the money they received was not only used to buy food, but for transport and taking care of children. However, paying for funeral policies was one on the most important things the recipients did with the money. When probing why the funeral policies were so important in their lives, most of the participants revealed that dying was always in their minds, especially now that they were living with HIV and they knew that they would not get healed from it. These findings were supported by the previous research done by Govender *et al* (2015). This indicated that "access to the DG is a life-line for patients on ART. When reporting that Temporary Disability Grants

play a crucial part in avoiding some of the costs that are associated with disability arising from HIV and AIDS and treatment costs" (Govender *et al*, 2015:9).

> *"I will continue to pay for the funeral society because you don't know what will happen in future. Society is something important and you have to pay for the society while still alive. You cannot depend on your mother or anyone else. If I pass on, or mother of the children or one of my children what will happen?" Participant I.*
>
> *"I wish it can be more because I have so many children and work for money is too many. I pay insurance from it". Participant D.*

During the interview, adherence was another theme that appeared in the importance of the disability grant in the lives of people living with HIV. Most of the participants stated that taking medication as prescribed was seen through the availability of food. The participants were able to buy food that they could eat before they take the treatment. That made them to maintain and keep the good report of taking the treatment as prescribed by the health practitioners. Moreover, they managed to avoid the pain that would be caused by taking medication without food.

As probing on the issue of defaulting on treatment went on, most of the participants revealed that if one does not take the medication in a prescribed way, it could cause problems such as side effects, reaction and resistance to the treatment of the disease. They concluded that the importance of the disability grant was that it helped them to buy food so that they could freely take their treatment. Otherwise the pain caused by the pills when taken on an empty stomach contributes to the default and non-adherence to the treatment. Participants were aware of the importance of adhering to treatment but bearing the pain overtook that responsibility.

The findings are generally compatible with the study conducted by Azia *et al* (2016), on 'Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa', maintaining that most of the respondents tend to miss their hospital schedules and/or their doses mainly because they do not

have enough money for transport fares or because they do not have money to buy food and eat properly so that they can take their medications as prescribed.

> *"I have not been sick since I take pills, they are treating me very well, but they do not want hunger, they need you to eat. If you eat them without food is not right." Participant G.*

> *"It helps me because I am the person that takes pills. I am the person that has no energy (weak). The pills are hurting me if I take them without food. I buy fruits and I eat." Participant D.*

> *"I don't have food and the pills are hurting me if I take them without food. Sometimes I end up not taking them because they hurt me when I take them without food. I drink HIV pills." Participant F.*

Participants realised the importance and contribution of Temporary Disability Grants in terms of being able to take their medication. They also appreciated the grant because when it was terminated they experienced the challenge of not taking their medication as it was causing pain when taken on an empty stomach.

4.3.3.3. No missed appointment for treatment

During probing on how the money was used, there was a similar pattern of answers revealing that there were no missed doctor's appointments. Most of the participants reported that the money they got as the disability grant was also used for transport to fetch the treatment. Moreover, the money was used to visit doctors for the participants' follow-ups. When probing, participants were asked if the money they received as the disability grant did bring the wellness in their lives, they revealed that the proper care that they received at the clinic led to their wellness as they were not missing their appointments. Most of the participants revealed that they were able to follow up on their appointment for the regular check-up on how they were doing. That also made it easier for the health personnel to detect if there were any side effects due to treatment. That statement was supporting the idea of wellness.

> *"It helps me because I am the person that takes pills. I buy fruits and I eat. It also helps when I go to people I dress nicely and it helps me with the children. Participant D*

Social relationships, empowerment and adherence and no missed appointments were seen as the important aspects brought by the temporary disability grants. As a result, the termination of the temporary disability grants removed all of that.

4.3.4. Increasing the time frame of receiving the disability grant can help to address the challenges.

The last objective of the study was investigating what can be done to increase the time frame for receiving the disability grant. From the feedback participants gave during the interview, it seemed obvious that some participants knew about when the Temporary Disability Grant would be terminated. However, they were not looking towards the termination of the grant. When they were asked during the interview why they were not looking forward towards the termination of the disability grant, participants mentioned that the time frame was very short as no one can just improve within six months.

During the interview, PLWHIV continued to say that they had been sick for a very long time and recovering within six months was impossible. They also informed the interviewer that it took time for their bodies to adapt to the medication, which sometimes made them sicker. The participants mentioned that the issue of adapting to the treatment must be considered and also the fact that they received the disability grant when they were seriously ill and that made their recovery slow. However, the grant was being terminated when they were still recovering from the illness.

> *"I was very sick and I should go to hospital. The clinic called the ambulance because I could not walk, I was very weak. I was discharged from the hospital. I stayed for 3 months till 2015" Participant D.*

Terminating a Temporary Disability Grant while someone has not yet recovered poses the problem of not recouping thus it makes them spend more money visiting doctors.

4.3.4.1. Amending rules for receiving the disability grant

During the interview, the participants were asked what could be done to increase the time frame for receiving the temporary disability grant. Most of the participants reported that the government should change the rules and criteria for receiving the grant. Changing of rules included that when a person is diagnosed with HIV, that

person should be eligible to receive the grant, regardless of his or her viral load. They continued to say just as when one is diagnosed one is immediately enrolled into the ARV regime, so the issue of receiving the disability grant should follow the same route.

When they were asked about the other criteria of receiving the disability grant such as the consideration of age and the employment status, most of them concluded that those criteria should be taken into account because the government would not be able to support those who are employed. When asked about age, they agreed that age should also be considered. If a person who is diagnosed with HIV is younger 60 years, he or she should get the disability grant, but the person who is 60 years should receive the old age grant not the disability grant.

Apart from the above, participants continued to raise the point of the issue of the six months receipt of the disability grant. As probing took place, they reasoned saying that it was not feasible for the recipients of the disability grant, especially those who were living with HIV to recover within six months. That was because it takes a long time for a person to become healthy. And it will also take a long time for a person's body to be strong enough for employment (Govender *et al*, 2015:7)

When they were asked why their bodies take a long time to recover, they mentioned that unlike other diseases that disable a human being, HIV and AIDS is very complicated as it does not only affect the body but also the mind of the person. Most of the participants mentioned that prejudice, lack of support from their partners, and poverty contribute to the raised stress levels faced by PLWHIV. When the interviewer probed around the issue of relationship between that high stress and the delay in the healing of the body, they claimed that increased stress affects their cd4 count. This affects their immune system and they experienced more infections as their immune system has deteriorated.

> *''Also my sister, she has this disease, she applied for it and after 6 months it was terminated. When she went to get the money, she was told that if there are still some tablets she is going to get healed. She has to work with her hands. They expected her to be healed within twelve months and that is so impossible''. Participant B*

The time frame for the receipt of the disability grant is too short and the criteria used to apply for the grant excludes those who have a high cd4 count from receiving the grant.

4.3.5. Application of the theoretical framework

4.3.5.1. The Health Belief Model

The Health Belief Model (HBM) which clarifies the role of beliefs in decision making to adhere to treatment regardless of the availability of food (Becker 1974:129-130) was used in the study. The study showed that participants were knowledgeable about how important it was it to take treatment accordingly confirms their Perceived Benefits according to HBM. They knew about how virus multiplies and the issues that can lead to the development of drug resistance, which further complicates the already limited second-and third-line treatment options available for patients. Most of the participants decided to keep on taking their treatments regardless of the termination of the temporary disability grant. They resorted to borrowing money from their neighbours. This, however, brought dissatisfaction from those neighbours, as most of the participants struggled to pay back the money due to the termination of their temporary disability grants.

4.3.5.2. Theory of Social Capital

The Theory of Social Capital, which is efficient at the meso level, refers to the group of people. It explains TDG as the money that can be utilized to make the micro-macro transition, meaning the money PLWHIV receive does not only support the recipient but their children and relatives.

The Theory of Social Capital as the social network proves that the Temporary Disability Grants improve the Social relationships of recipients with other people like their neighbours. Kagee (2014:3), argued that social capital played an important role in adherence behaviour. When interviewed, most of the participants stated that the Temporary Disability Grant had contributed positively to their social relationship with other family members and their neighbours. Bonds social capital also support that most of the participants took care of the neighbours with the money they received as the disability grant. Although the money that people living with HIV received was meant strictly to help the recipients, due to the poverty the community is facing, even the neighbours of the disability grant recipients did benefit from it.

4.6. Conclusion

In this chapter data was analysed, and factors that were related to challenges experienced by PLWHIV on the termination of the disability grant were analysed according to the objectives of the research. These were: exploring the challenges experienced by PLWHIV on the termination of the disability grants which revealed poverty, scarcity of food and non-adherence to be the challenges. Learning about the effects of the termination of their Temporary Disability Grants exposed poor management of HIV and AIDS by PLWHIV facing the AIDS stage. The study also investigated what could be done to increase the time frame for receiving the disability grant. The participants mentioned that the issue of adapting to the treatment must be considered and also the fact that they received the disability grant when they were seriously ill made the recovery to be slow and the grant was terminated when they were still recovering from the illness. Finally, the theories that were used as the framework of the study were applied to the challenges experienced by PLWHIV on the termination of the temporary disability grant.

Chapter 5: Conclusion and Recommendations

5.1. Introduction

This final chapter will focus on discussion, conclusion and recommendations as well as the implications and limitations of the study. The first part of the chapter examines the findings obtained in relation to the objectives of the study namely: to explore the challenges faced by PLWHIV on the termination of the disability grant, to understand the effects the termination of disability grants on the lives of people living with HIV/AIDS (PLWHIV), to explore the importance of the Temporary Disability Grant (TDG) in the lives of people living with HIV (PLWHI), and to investigate what can be done to increase the timeframe of receiving Disability Grant. The findings of the study are discussed in line with the themes and categories that were derived from the data.

5.2. Challenges experienced by PLWHIV when their disability grants are terminated.

The findings revealed that termination of the disability grant resulted in challenges like poverty, scarcity of food before one can take the treatment and non-adherence to treatment. Food was seen as the necessary vehicle for medication taking. The food was needed before one could take medication due to the pain it caused when taken without food.

However, avoiding the pain was an immediate concern. Regardless of the results that contributed by not taking medication regularly, only the presence of food meant taking medication accordingly. Having said that, the scarcity of food was found to lead to the non-adherence to medication.

The findings also showed that poverty led to insufficient money for the transport to fetch medication, which on the other contributes to non-adherence. Many participants reported that they sometimes failed to take their antiretroviral treatment (ART) because they are poor and unemployed; therefore, they could not raise enough money to buy food which needed to be eaten before taking the medication. Participants also mentioned that sometimes they did not have money for the taxi fare to collect their treatment.

Nonetheless, according to this study, the termination of the disability grant seemed to be the major factor that had contributed to non-adherence.

5.3. The importance and the contribution the Temporary Disability Grants (DG) in the lives of PLWHIV

An Improved livelihood and the ability to move around looking for a job was seen as the important contribution of the disability grant in the lives of the people living with HIV. The Temporary Disability Grant contributed money to buy food and money for taxi fare for collecting treatment.

5.3.1. Employment status and wellness of the recipients

The study discovered that the disability grant is very crucial in the lives of people living with HIV. Its importance was seen through the following aspects: employment status of the recipients. It showed, the termination of Temporary Disability Grant was left the recipients with no income as they depended solely on the grant. The wellness of the participants was seen through the gaining of body weight and being healthy. That was because they could afford to buy healthy food that contributed to their healthy bodies. Their CD4 count also improved and they did not get sick so often.

5.3.2. Social relationships

The study found out that the importance of disability grant was seen in the social relationships of disability grant recipients and their neighbours. With the money the recipients received from the grant, they were able to share the food they bought with their neighbours. The Theory of Social Capital supports the notion of the act that money can be utilized to make the micro-macro transition. This means the money PLWHIV receive do not only support the disability grant recipient, but also other family members. The money is used for paying for children's school fees and helping their neighbours (Tzanakis 2013:5). Moreover, the recipients shared what they had with their neighbours and they were not under the pressure of borrowing money and asking food from their neighbours.

5.3.3. Adherence

The study also showed that adhering to treatment was one of the important benefits of receiving the disability grant. Adherence is the ability of patients to stick to and follow treatment plans, to take medication as prescribed at prescribed times and frequencies and also to follow restrictions regarding lifestyles, food and other medication

(Govender *et al* 2015:5). The study also discovered that participants were able to buy food and collect medication, and as such they were taking their medication as it was prescribed by their doctors. The majority of participants acknowledged that scarcity of food contributed to non-adherence of the treatment.

More findings on the importance of disability grants were that the disability grant recipients did not miss their appointments for collecting their treatment and for their medical check-ups. The reason was that they were able to pay for transport to fetch the treatment. It enabled them to meet either fully or partially the healthcare related costs including transport, food or other household costs and enabled treatment access." (Govender *et al* 2015:9). Furthermore, economic empowerment was about the ability to use and budget with the money they received as disability grant.

The importance of Temporary Disability Grant in the lives of people living with HIV also confirmed their economic empowerment through being able to pay for their children's school fees, take care of their households and also being able to pay for their funeral policies.

However, there were effects of the termination of Temporary Disability Grants cited by the participants. Termination of Temporary Disability Grant was found to affect the children of the recipients. The reason was that the parents could not afford to pay for the school fees, they also could not afford to buy clothes for their children as they were no longer receiving the grant. Apart from that, the termination had contributed to a circle of poverty, as the children could not get education that would enable them to be employable.

The study discovered that being diagnosed with HIV was not the only challenge the participants were facing. Knowing that one is not going to heal from the disease posed a huge challenge that also lead to stress. The reason was that HIV weakens the body and that imposes the challenge of not being able to find a job.

Additionally, most of the participants experienced a lot of pressure when taking care of the family on their own, while their partners refused to help with providing for the family.

5.5. Extension of time frame to receive temporary disability grant

The study showed that termination of temporary disability grant was another huge challenge the people living with HIV were facing. Although participants were aware that at some stage their grant would be terminated, and they would have to renew it if they qualified to do so. There were other challenges the participants experienced when they were renewing their grants. Challenges like lack of information on how one had to renew the grant. Not knowing what to do as there was no clear procedure one had to follow when renewing disability grant which led to poor treatment (Govender *et al* 2015:6). The participants were sent back home without proper explanation on what to bring, where to get the documents needed, and which office they should take the documents to. The study disclosed that the money the participants were using to go back and fro to renew their grants was another challenge as they were using money that they did not have (Kagee 2014:6).

Finally, the study revealed that most of the participants wished that the rules for receiving the grant could be amended and the time frame be increased. That was because most of the participants reported that they could not get healthy within the six months period of the grant as most of them received their grants when their immune system were very low and they were already facing opportunistic diseases like TB (tuberculosis).

5.6. Limitations of the research

This analysis has concentrated on how people living with HIV are affected by the termination of the Temporary Disability Grant, not mentioning other types of disabilities. Moreover, the findings of this study are limited to people who are part of the support groups at Ekupholeni Mental Health and Trauma Centre. Nevertheless, the findings of this study do not imply that all the people who live with HIV and receive Temporary Disability Grants are affected by the termination of grant the same way as the participants that were interviewed from Ekupholeni Mental Health and Trauma Centre.

Finally, qualitative research is in many ways subjective and the experiences and feelings of the researcher may have influence on the research. Finally, the study was about HIV and AIDS. Due to the stigma that is associated with HIV, it is still difficult for

some people to talk about the issues surrounding HIV. This might have affected the targeted number of recruited participants.

5.7. Recommendations

The termination of the Temporary Disability Grant has posed several challenges in the lives of PLWHIV and mostly it has affected the management of HIV and AIDS. But working with support groups can help to curb the high numbers of non-adherence and new infections. For that reason, the following recommendations are made based on the programme level and research.

5.7.1. Programme level

The NGOs can work with PLWHIV in educating them about how to produce their own food. This can be done by donating seeds and seedlings and helping them to start their own gardens. Continuous psychosocial support and formation of more support groups could also help to promote adherence. Moreover, encouraging more males to attend the support groups as they are affected by termination of Temporary Disability Grant like their female counterparts.

5.7.2. Further research

Without further research into how temporary and permanent disability grant can help in the proper management of HIV and AIDS; it will not be possible to deal with new infections of HIV, which continues to leave children as orphans and take its toll in the economy of the country as more and more people are supposed to be enrolled into treatment. If the procedure for receiving the disability grant can change, this will assist in achieving the National Health Insurance (NHI) plan of 2030 which states that by 2030 90% of people should have been taken HIV test and 90% of patients who are on ART should have CD4 count of zero. This will lead to better management of HIV and AIDS in South Africa.

5.8. Conclusion

The key findings of this study is that in a context of chronic unemployment and high levels of poverty, unemployment and HIV and AIDS, these are important predictors of access to the TDG, which in turn serves as the poverty relief for people who are not working and live with HIV. In addition, the availability of the disability grant helps with the adherence to the ARVs and proper management of the disease because of the availability of food and money for transport. The availability of the Temporary Disability

Grant also helps with the proper management and running of households because of the money the PLWHIV are getting from the disability grant.

LIST OF REFERENCES

Adefolalua, A, Nkosia, Z, Olorunjub, S & Masemola, P. 2014. Self-efficacy, medication beliefs and adherence to antiretroviral therapy by patients attending a health facility in Pretoria. *South African Family Practice* 56(5):1–5.

Afe, AJ, Motunrayo, & Ogungbade, GO. 2017. Explaining Adherence to HAART among Patients Living with HIV/AIDS in Nigeria: Behavioral Theory Analysis. *Journal of AIDS & Clinical Research* 8(8):1-8.

Anney, VN. 2014. Ensuring the quality of the findings of Qualitative Research: Looking at Trustworthiness Criteria. Scholar link Research Institute Journal. *Journal of Emerging Trends in Educational Research and Policy Studies* 5(2):272-281.

Azia, IN. Mukumbang, FC. & Van Wyk, B. 2016. Barriers to adherence to antiretroviral treatment in a regional hospital in Vredenburg, Western Cape, South Africa. South *African Journal of HIV Med* 17(1):1-8.

Babbie, E. 2013. *The practice of social research*. 13th edition. Belmont, CA: Wadsworth.

Babbie, E. 2011. *The practice of social research*. 12th edition. Belmont, CA: Wadsworth.

Blaxter, L, Huges, C & Tight, M. 1998. *How to research.* Buckingham: Open University Press.

Braum, V & Clark, V. 2013. *Successful qualitative research: A practical guide for beginners*. London: Sage.

Campbella, C, Scotta, K, Nhamoa, M, Nyamukapab, C, Madanhire, C, Skovdalc, M, Sherrd, L & Gregson, S. 2013. Social capital and HIV Competent Communities: The role of community groups in managing HIV/AIDS in rural Zimbabwe. *AIDS Care* 25(1):114-122.

Carpenter, CJ. 2010. A Meta-Analysis of the Effectiveness of Health Belief Model Variables in Predicting Behavior. *Health Communication* 25(8):661-669.

Christensen, L, Johnson, R & Turner, L. 2011. *Research methods, Design and Analysis*. 11th Edition. Pearson.

Collins English Dictionary. 2016. Macmillan.

Fusch, PI & Ness, LR. 2015. Are We There Yet? Data Saturation in Qualitative Research. *The Qualitative Report* 20(9):1408-1416.

Govender, V, Fried, J, Birch, S, Chimbini, MN & Cleary, S. 2015. Disability grant: a precarious lifeline for HIV/AIDS patients in South Africa. *BMC Health Services Research* 15(1):1-10.

Gutura, P & Tanga, T. 2014. The Intended Consequences of the Social Assistance Grants in South Africa. *Mediterranean Journal of Social Sciences* 5(2):1-13.

Haber, N, Fink, G, Bärnighausen, T, Bor, J, Cohen, J & Tanser, F, Pillay, D & Fink, G. 2017. Disability for HIV and Disincentives for Health: The Impact of South Africa's Disability Grant on HIV/AIDS Recovery. Working paper draft v1.2.

Hawkins, RL & Maurer, K. 2010. Bonding, Bridging and Linking: How Social Capital Operated in New Orleans following Hurricane Katrina. *British Journal of Social Work* (1)40:1777–1793.

Hofisi, C, Hofisi, M & Mago, S. 2014. Critiquing Interviewing as a Data Collection Method. *Mediterranean Journal of Social Sciences* 5(16):1-5.

Hunt, CA, Durham, WH & Menke, MC. 2015. Social Capital in Development: Bonds, Bridges, and Links in Osa and Golfito, Costa Rica. *Human Organization* (74)3:217-229

Kagee, A. 2014. Do disability grants influence adherence to antiretroviral therapy? Department of Psychology, Stellenbosch University, South Africa. Opinion Paper.

Kelly, G. 2013. Regulating access to the disability grant in South Africa, 1990-2013. CSSR Working Paper No. 330. December, 2013.

Knight, L, Hosegood, V & Timaeus, I. 2013. The South African disability grant: influence on HIV treatment outcomes and household well-being in Kwazulu-Natal. *Development Southern Africa* 30(1):135-147.

Kumar, R. 2014. *Research methodology: a step by step guide for the beginners*. 4th edition. London: Sage.

Leibbrandt, M, Lilenstaein, K, Shender, C, & Wooland, I. 2013. The influence of social transfers on labour supply: A South African and international review. Working Paper Series Number 112.

Manuela de Paoli, MM, Mills, EA & Grønningsæter, AB. 2012. The ARV roll out and the disability grant: A South African dilemma? *Journal of the International AIDS Society* 15(6):1-10.

Marshall, C & Rossman, G. 1999. *Designing qualitative research*. 3rd edition. London: Sage.

Masoudnia, E. 2015. Public perceptions about HIV/AIDS and discriminatory attitudes toward people living with acquired immunodeficiency syndrome in Iran, SAHARA-J: *Journal of Social Aspects of HIV/AIDS* 12(1):116-122.

Meeus,S & Gulinck, H. 2008. Semi-Urban Areas in Landscape Research: A Review. *Living Rev. Landscape Res* 2(3):1-45.

Moattar, M, Roozitalab, M, Gholamzadeh, S, Firoozi, M & Zare, N. 2014. Practical Application of Health Belief Model to Enhance the Uptake of Colorectal Cancer Screening. *Journal of Community Med Health Educ* 4(4):1-5.

Mukoswa, GM, Charalambous, S & Nelson, G. 2017. The association between social capital and HIV treatment outcomes in South Africa. *PLoS ONE* 12(11):1-13.

Neumann, T & De Freitas, S. 2009. The use of the exploratory learning for supporting immersive learning in virtual environment. *Computers and education* 52(2):343-352.

Nuwagaba, EL, Nakabugo, M, Tumukunde, M, Ngirabakunzi, E, Hartley, S & Wade, A. 2012. Accessibility to micro-finance services by people with disability in Bushanyi District, Uganda. *Disability and Society* 27(2):175-190.

Omole OB, Semenya M-AML. Treatment outcomes in a rural HIV clinic in South Africa: Implications for health care. *Southern African Journal of HIV Medicine* 17(1)1-6.

Okeke, C & Van Wyk. M. 2015. *Educational Research: An African Approach*. Oxford University Press Southern Africa. South Africa.

Peltzer, K. 2012. Social grant for people living with HIV and on antiretroviral therapy in Kwa-Zulu Natal, South Africa: A longitudinal study. *Journal of Social Aspects of HIV/AIDS* 9(1): 6-14.

Pienaar, M, Van Rooyen, F & Walsh, M. 2017. Household food security and HIV status in rural and urban communities in the Free State province, South Africa. SAHARA-J: *Journal of Social Aspects of HIV/AIDS* 14(1): 118-13.

Punch, K. 2011. *Introduction to social research*. 2nd edition. London: Sage.

Ragin, CC. 1994. *Constructing social research*. Thousand Oaks: Pine Forge.

Rocco L. & Suhrcke M. 2012. Is social capital good for health? A European perspective. Copenhagen, WHO Regional

Rosenstock, IM. 2016. Historical Origins of the Health Belief Model. *Health Education Monographs* 4(2):328-335.

Setswe, G. 2015. HIV/AIDS, inequality and social justice in South Africa. World social science forum 13-16 September 2015.

Shenton, K. 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information* (22) 63–75.

Shubber, Z, Mills, EJ, Nachega, JB, Vreeman, R, Freitas, M & Bock, P. 2016. Patient-Reported Barriers to Adherence to Antiretroviral Therapy: A Systematic Review and Meta-Analysis*. PLoS Med* 13(11):1-14.

Smart, J. 2014. *Models of disability: Implication for practise*. Rehabilitation Counselling Program. Utah State University.

Tarkang, E & Zotor, B. 2015. Application of the Health Belief Model (HBM) in HIV Prevention: A Literature Review. *Central African Journal of Public Health* 1(1):1-8.

Tola, H, Shojaeizadeh, D, Tol, A, Garmaroudi, G, Yekaninejad, M. Kebede, A. Ejeta, L & Kassa, D. 2016. Psychological and Educational Intervention to Improve Tuberculosis Treatment Adherence in Ethiopia Based on Health Belief Model: A Cluster Randomized Control Trial. *PLoS ONE* 11(5):1-15.

Tzanakis, M. 2013. Social Capital in Bourdie's, Coleman and Putnam's theory: empirical evidence and emergent measurement issues. *Educate* 2(13):2-23.

Wagner, C, Kawalich, M & Garner, M. 2012. *Doing Social Research*. A global Context. UK: McGraw-Hill.

Wright, PA, McSweeney, JC, Frith, SE, Stewart, KE & Booth, BM. 2009. Losing all the piece: Qualitative study of HIV risk perception and risk reduction among rural African American women who use cocaine. *Proquest Social Science Journals* 39(3):577-605.

WHO. 2011. World health statistics. Available at: http://www.who.int/whosis/whostat/2011/en (Accessed on 16/11/2017).

WHO. 2015. Global Health Observatory (GHO) data. Available at: http://www.who.int/gho/hiv/en/ (Accessed on 15/10/2017).

WHO. 2015. The global HIV/AIDS epidemic. Fact sheet number 360. Updated in July 2015.

UNAIDS. 2016. HIV and AIDS estimates (2016). Available at: http://www.unaids.org/en/regionscountries/countries/southafrica. (Accessed on 20/11/2017).

UNAIDS. 2016. Prevention Gap Report summary. Available at: http://www.unaids.org/sites/default/files/media_asset/2016PreventionGapReportsummary_en.pdf (Accessed on 15/11/2017).

APPENDIX A: letters asking for permission

Mpolokeng Moetseloa

8295 Leondale Gardens

ROODEKOP EXT.11

16/08/2015

The Director

Ekupholweni Mental Health Centre

Natalspruit Hospital

Dear Madam

I am a student in Masters in Social Behavioural Studies in HIV and AIDS at the University Of South Africa (UNISA) and as part of my studies I am required to conduct research on a social problem. I have identified a need for research into 'The challenges experienced by the people living with HIV on the termination of disability grant in a semi-urban area in Gauteng'.

I am writing to ask if it would be possible to recruit participants for this study from your organisation. I have chosen to work with your organisation because it works with people with different psychosocial problems including HIV. This study may in future give rise to more specific way of dealing with renewal of disability grants.

The study will be conducted on the qualitative research method using qualitative interviews. Tape recorder will be used to record the responses the participants will be giving pertaining to the questions. The questions will be asking about the challenges experienced by people living with HIV on the termination of the disability grant. I would like to begin collecting data in September 2015, but I am very happy to be guided by you on this.

I hope that you find the attached project interesting and you will be interested in working with me on it.

Please feel free to contact me on 073 801 0345, email address: mpolomoetse@yahoo.com if you have any queries, or you can contact my supervisor

Mr Roets: 012 429 6975, email Address: roetshjl@unisa.ac.za

Yours faithfully

Mpolokeng Moetseloa

(Student no: 40798037)

RE: Research

- Antje Manfroni
-
- May 31, 2013

To

- 'Mathapelo Nkadimeng'
- mpolokeng moetseloa

Good Day, Mpolokeng.

If you wish to conduct research at Ekupholeni Mental health and Trauma Center, we need a full proposal, a letter saying that the Ethics Committee of your university has approved, and the contact details for your supervisor.
I will then present these documents to our Board for approval.
The reason for this process is that we deal with severely traumatized adults and children and have to ensure that they are not inadvertently come to harm in any way.

Kind regards

Antje Manfroni
Clinical Psychologist
Director: Ekupholeni

-----Original Message-----
From: Mathapelo Nkadimeng [mailto:ekuoffice@icon.co.za]
Sent: 30 May 2013 02:37 PM
To: 'Antje Manfroni'
Subject: FW:

Hi Antje

Below is a letter from Mpolokeng.
Please help her if you can.

Regards
Mathapelo

-----Original Message-----

APPENDIX B: Interview guide

Interview guide

I am a student from UNISA conducting interviews to try to understand the challenges faced by the people who live with HIV on the termination of the disability grant. I have an informed consent form for you which you will sign to indicate that you have received information about this study and agree to participate. It will also inform you that the interview will be recorded, and transcribed.

Location: Ekupholweni Mental and Trauma Centre

Time allocation: 45 minutes per respondent

Date: 01/11/2016

Interview questions/schedule

Profile of the respondent questions

- How old are you?
- How many are in your family?
- What is your employment status?
- How many are adults in your family?
- What ages are the adults in the family?
- What ages are the children in the family?

Main questions

1. What are the challenges experienced by PLWHIV when temporary disability grants are terminated?

2. What are the effects of the termination of temporary disability grants in the lives of PLWHIV?

3. What is the importance of and the contribution made by the Temporary Disability Grants (TDG) in the lives of PLWHIV?

4. Can increasing the time frame for receiving the temporary disability grant help to address the problems caused by the termination of the disability grant?

Probing questions

- Who is eligible for the grant?
- What do you know about the termination of the temporary disability grant?
- At what stage does a disability grant be terminated?
- What problems did you experience before you received your disability grant?
- After your grant had been terminated, how long did it take to resume receiving your grant again?
- Describe how the disability grant assists you
- What problems did you experience when your disability grant was terminated?

Closing

Are there any responses you would like to add or any questions that you would like to ask about anything we discussed or that took place during this interview? Thank you very much for your time.

APPENDIX C: informed consent form

INFORMED CONSENT FORM

TITLE OF RESEARCH PROJECT:

THE CHALLENGES EXPERIENCED BY THE PEOPLE LIVING WITH HIV ON THE TERMINATION OF TEMPORARY DISABILITY GRANT IN A SEMI-URBAN AREA IN GAUTENG

NATURE AND PURPOSE OF THE STUDY

The purpose of this research is to investigate the challenges experienced by the people living with HIV on the termination of a disability grant. To gather this information the disability grant recipients will be interviewed.

RESEARCH PROCESS

1. The study requires your participation by signing a consent form

2. The interview will be conducted by the researcher.

3. There are no right or wrong answers and all opinions will be valued.

4. You do not need to prepare anything in advance.

NOTIFICATION OF THAT THE INTERVIEW WILL BE TAPE RECORDED

The interview will be tape recorded to ensure that valued information picked up during the interview is captured and the context of the information can be reviewed in detail. Following the interview, the recorded material will be transcribed.

CONFIDENTIALITY

Participant's opinions are viewed as strictly confidential and only members of the research team will have access to the information. No data published in dissertations and journals will contain any information through which participants may be identified. Your anonymity is therefore ensured.

WITHDRAWAL CLAUSE

I understand that I may withdraw from the interview at any time. I therefore participate voluntarily.

POTENTIAL BENEFITS OF THE STUDY

The benefits of the study are to sensitize the government about the damage the termination of disability grants does to the lives of people living with HIV. This study may in future give rise to more specific ways of dealing with the renewal of disability grants and the implementation of a Chronic Diseases Grant. At the conclusion of interviews, participants will not be compensated for their contribution but their participation will be highly appreciated.

INFORMATION (contact information of the supervisor)

Should you have any questions concerning the study, please contact the supervisor, L. Roets at the Department of Sociology, Main Campus, UNISA, Tel.012 429 66684

CONSENT OF THE UNDER SIGNED

I …… (full name) have read the above information relating to the project and have also heard the verbal version, and declare that I understand it.

Signature of participant: .....

Signed at …… on ……

APPENDIX D: Ethical clearance